

Irish Motor Neurone
Disease Association

Annual Report 2022



Irish
Motor
Neurone
Disease
Association



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**UNTIL THERE
IS A CURE,
THERE IS CARE**



OUR HIGHLIGHTS FOR 2022



18,543

Nursing Support Calls & Emails



787

Home Visits



120

Professional Education & Information Sessions Held



560

Clients & Families Supported



16,000

Health Care Professionals Accessed our Service



€769,593

Spent on Specialised Equipment



€3,090,795

Raised



14,700+

Home Care Hours Funded



89c

Out of every €1 goes directly on support services

“The work that was done by the IMNDA for our family is greatly appreciated and will always be remembered by us. Our thanks to all in IMNDA”

MESSAGE FROM OUR CHAIRPERSON

This is my first time communicating with you as Chairman of IMNDA, and I would like to say it is a tremendous honour to have been asked to lead this incredible organisation. As I write, our organisation is busier than ever, both with the number of people being supported and the breadth of the work being undertaken by our hardworking team.



The size and scale of IMNDA is a tribute to the former Chairman, Dr Declan McDaid, who stood down in 2022 having completed eleven incredibly successful years in the role. Declan, for your service and dedication we are truly grateful.

I would also like to take this opportunity to express the thanks of the entire organisation to Charlie Bird, whose tireless fundraising efforts have given IMNDA room to manoeuvre as we deal with an ever-increasing workload. Climb with Charlie has allowed us to recruit a sixth full-time community nurse, extra funding for research, new options for respite breaks, improved transport to and from clinics, and in time, residential respite services at dedicated facilities.

My goal as Chairman is to continue the good work that has gone before, and to expand IMNDA to provide care not just for those living with the illness, but to their families and carers as

well. Our ethos as an organisation is to provide whatever support we can. And we realise the impact that MND has on entire households. So, while we will continue to provide equipment and expert nursing care, we will look at how we can help others whose lives are impacted in every household.

I would also like to take the time to thank the efforts of every community fundraiser the length and breadth of Ireland. Without you, we simply wouldn't exist. We promise to continue to respect the funds you raise for IMNDA and put every cent to the best possible use. Our goal remains a world without MND. Until that time, we will continue to travel the road together.

Jonathan Healy

MESSAGE FROM OUR CHIEF EXECUTIVE

As we look back on the year of 2022, the words “thank you” seem to be the most appropriate opening to our Annual Report.



2022 will be remembered by all of us at IMNDA as a very significant and a very special year. On a dark and cold January 7th, Charlie Bird and his wife Claire appeared on

the Late Late Show and declared their intention of climbing Croagh Patrick in support of IMNDA and Pieta. What began as a couple’s steely determination to undertake a personal challenge with family and friends, became one of the most successful fundraising campaigns ever undertaken for IMNDA.

With a small fundraising team and working with our colleagues at Pieta, we worked tirelessly to put in place a sound basis for the organisation of such an event planned for Saturday, April 2nd, 2022. What we underestimated was the sheer extent of the support that we would receive from our MND community, both at home and abroad. Hundreds of climbs and walks were

organised in all parts of Ireland with additional events scheduled across Europe and beyond. It was without a doubt, a phenomenal response to Charlie’s plea for support to his cause that was as he repeated so often “so close to his heart”.

“Climb with Charlie” achieved over €1.7 million for IMNDA. These monies were ring-fenced for direct support to those affected by MND and were aptly named the “Charlie Bird Development Fund”. To give a voice to our clients and families, we conducted a national survey to ask how this money should be spent. And we responded to that collective voice.

We recruited an additional specialist MND nurse to support our clients in their home, we supported a European research programme under Professor Orla Hardiman looking at targeted therapies for those with MND, we invested in a voice banking service, and we began the process of delivering very practical supports for transport, family breaks and respite care. 2023 will see the completion of this work.

None of this work would have been possible without the generosity of the

people of Ireland who got behind this campaign. We know our loyal MND community supported it hugely and we can confidently say that what we achieved in this one campaign would not have been possible without the support of everyone, in every part of the country. So, thank you one and all for your unending loyal support.

Our deepest appreciation will forever go to Charlie Bird and Claire, for their work in creating this remarkable fund that will go such a long way in improving the lives of those living with MND over years to come. What they have achieved in raising these significant funds is incredible but more significantly they have succeeded in raising the level of awareness of MND itself, its effects on body and soul as well as the enormous challenges faced by the entire family as they navigate its journey.

During 2022, we also received the news that we were the beneficiary of a hugely significant donation from the generous J P McManus Foundation to support our work nationally. Recognising the importance of home support for those with MND, we were provided with the funds to employ an additional nurse to provide this valuable support to those in the South / Mid-Western region. For many years, our small team of nurses (which started off with just one nurse) struggled to meet clients in their homes as they covered huge territories and long distances. This expansion of the team has eliminated this and ensured that our clients and their families receive the care they need and in a timely manner.

A special mention to Dr John Drumm, our friend and advocate for MND in

Limerick who went above and beyond the call of duty to ensure that this significant donation was pursued and indeed, achieved. A remarkable man himself battling MND, he worked tirelessly to ensure that this donation became a reality. A true advocate for those living with MND.

2022 was a very good year for IMNDA and we were helped along by so many kind and generous people, both with their time and help and we would like to acknowledge this very generous and truly wonderful support. We are a small team and with the support of our Chair and Board members, external advisors, those who simply offer their help at events and those who raise significant amounts of money in their communities – thank you from the bottom of our hearts.

Finally, we know that many families have lost loved ones during 2022 and these losses are our losses as members of our community. We think of you at this difficult time, and you are highest in our thoughts and prayers as we reflect on the year gone.

With thanks and my very best to you all,

Lillian McGovern

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SUMMARY OF PURPOSE

About IMNDA

Irish Motor Neurone Disease Association (IMNDA) was established on 1st May 1985 by a small group of friends, relatives and caregivers of people with Motor Neurone Disease.

Motor Neurone Disease (MND) is a progressive neurological condition that attacks the motor neurones, or nerves, in the brain and spinal cord. This means messages gradually stop reaching muscles, which leads to weakness and wasting.

MND affects the everyday things we take for granted. It can affect how you walk, talk, eat, drink and even breathe. MND strikes people of all ages and there is currently no cure.

Irish Motor Neurone Disease Association (IMNDA) is the primary care and support organisation for people living with MND, their families, caregivers and friends.

There are over 400 people living with MND in Ireland. MND is often referred to

as the 1,000 day disease as most people die within 1,000 days of symptom onset.

During these 1,000 days someone with MND gradually loses control of their limbs ultimately resulting in a loss of independence. IMNDA aims to alleviate frustration, fear and anxiety that is often felt by the whole family.

Our key services include:

- Home visiting by our 5 MND Nurses
- Financial assistance towards home care
- Providing specialist medical equipment free of charge to our service users
- Supporting research into the causes and treatments of MND
- Freephone Helpline & Information service for our members



Great organisation with a range of practical but necessary support services to those of us coping with MND.



Mission Statement

Our Vision

A World Free of MND

Our Mission

To support people with Motor Neurone Disease (MND), their families and carers through advocacy, home and professional support

Our Values

- To enable people with MND to live as active independent citizens
- To empower people with MND to make informed decisions
- To put people with MND at the heart of our focus
- To ensure that people with MND have a voice by advocating on their behalf
- To value everyone who contributes to our association
- To value everyone who works for our association

Key Objectives

- To encourage and promote the best methods of care, education, research and treatment for people living with MND throughout Ireland.
- To establish and promote models of good practice in the delivery of specialised services to people living with MND, their families and carers.
- To raise awareness of Motor Neurone Disease in the wider community.



1,000 DAY DISEASE

1 person dies every 3 days



MND is the PITS – progressive, incurable, and terminal

MND is a rapidly progressing disease that affects the brain & the spinal cord



MND affects the nerves that control movement so muscles no longer work – it does not usually affect the senses such as sight, sound, feeling etc

Around 35% of people will experience mild cognitive change causing difficulties with planning, decision-making and language



A further 15% will experience a form of dementia resulting in more pronounced behavioural changes



MND does not discriminate – it affects people of all ages from all walks of life

MND is known as the 1000-day disease. During these 1000 days someone with MND gradually loses control of their limbs ultimately resulting in a loss of independence. Everyday things we take for granted like walking, talking and eating may become virtually impossible.

The journey with MND is a series of losses. IMNDA aims to alleviate frustration, fear and anxiety that is often felt by the whole family.

The support IMNDA gives to people and families living with MND is truly outstanding. Thank you all for the help you gave my husband and us during our journey.

IMNDA IS HERE TO HELP

We consistently provide support and care to over 400 people living with Motor Neurone Disease at any one time. Everybody's requirements vary but we are here regardless of when and how we are needed.

The families of anyone that unfortunately has to use the services of IMNDA will never be able to repay them for their support and kindness.

Our services are immediate and free of charge. IMNDA is a small organisation achieving big things in the fight against MND. Donations to IMNDA allow us to provide our pivotal and specialist services. Without fundraising and donations, we would not be here.

85% of our income comes from the generosity of the general public

Every bucket shook, every race ran, every Christmas card bought, every donation sent in and every table quiz held, ensures a person who needs help gets it, regardless of where they live in Ireland and their financial situation.

IMNDA's resources are at an all-time high. At any one time approximately 400 people have MND in Ireland. That is 400 personal battles. 400 shell shocked families coming to terms with the distressing symptoms of MND. 400 families who would have nowhere else to turn without IMNDA.

Where the money goes

In 2022, IMNDA spent the monies raised in the following way:

- 89% went directly towards services we provide to families living with MND
- 11% relates to the costs of raising funds to ensure we always have a steady income
- 89 cent of every euro raised goes directly towards services

Together we make a real difference – MND is relentless and so are we

Without your consistent support, IMNDA would not be able to continue offering financial, emotional, and practical support to those who so desperately need it.

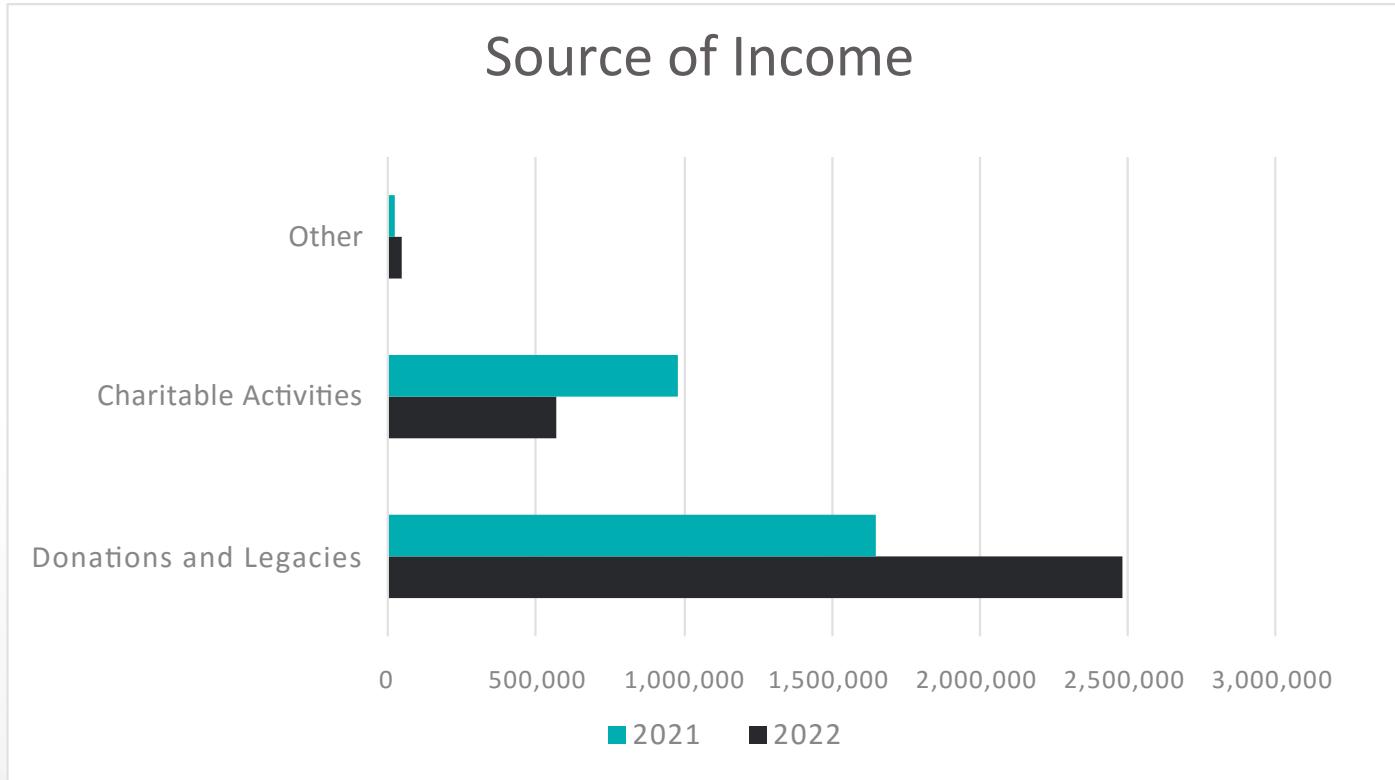


2022 FINANCES

TOTAL INCOME

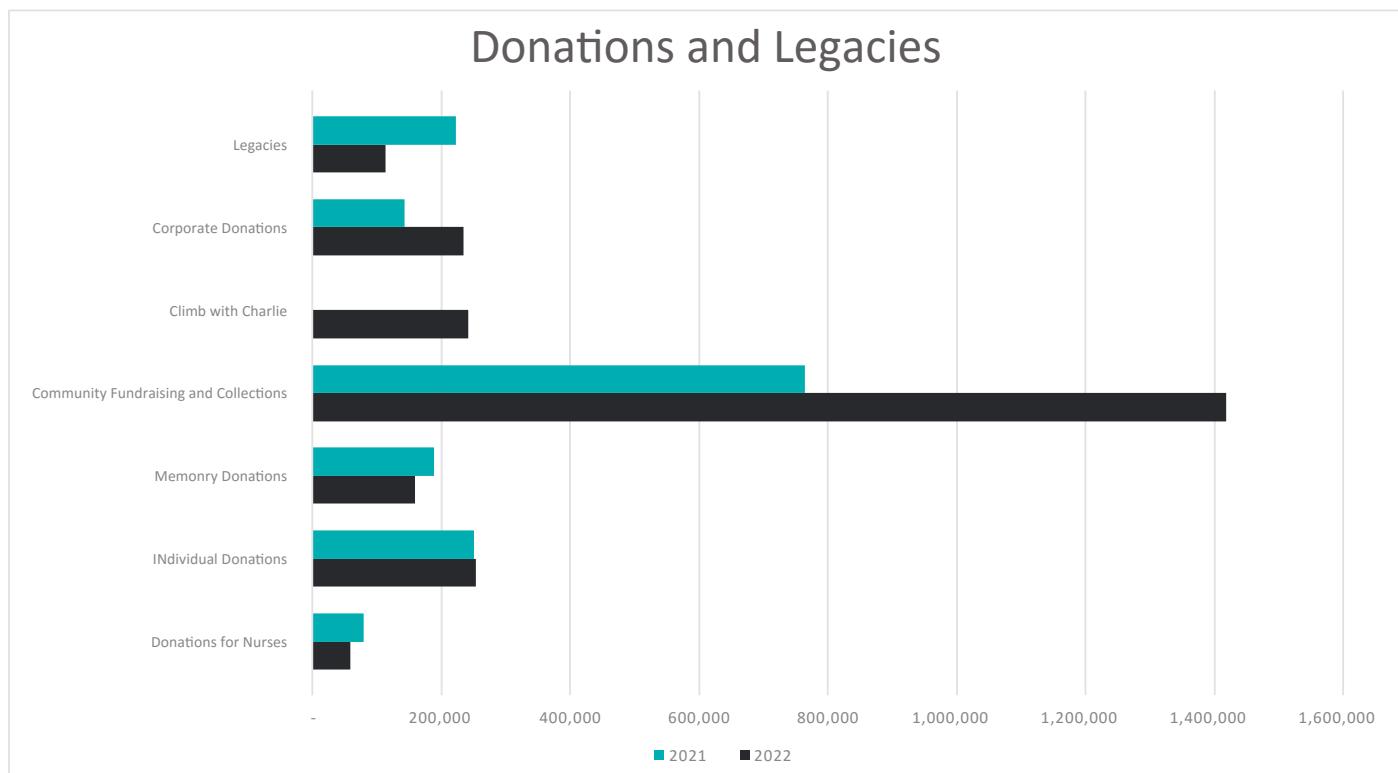
2022 was really a record-breaking year in terms of fundraising. The total income amounted to €3,090,795 (2021 €2,648,134), which was an 11% increase on 2021. This was all down to the fantastic and continued backing that we receive from our donors.

How Money Was Raised

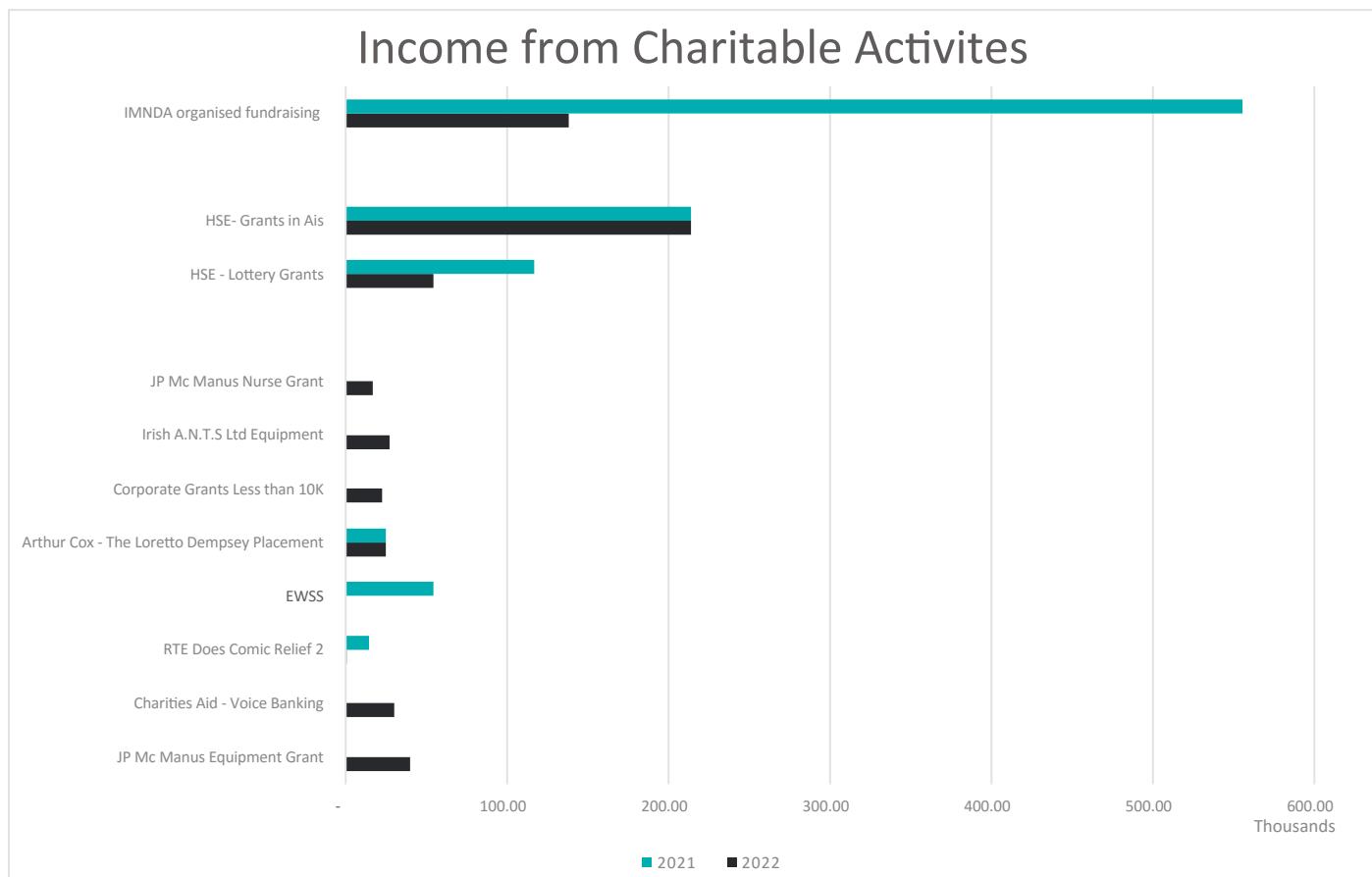


In 2022, 80% of our income came from donations and legacies (62% in 2021). 18% of our income came from charitable activities (37% in 2021). 1% came from Other Trading Activities (0.6% in 2021) and 1% from interest realised from investments.

Donations & Legacies



Community events taken on by our amazing MND community was considerably higher than in 2021. A total of €1,417,623 was raised. The increase in income is down to the dedication, commitment, and loyalty of our supporters. Thank you everyone!



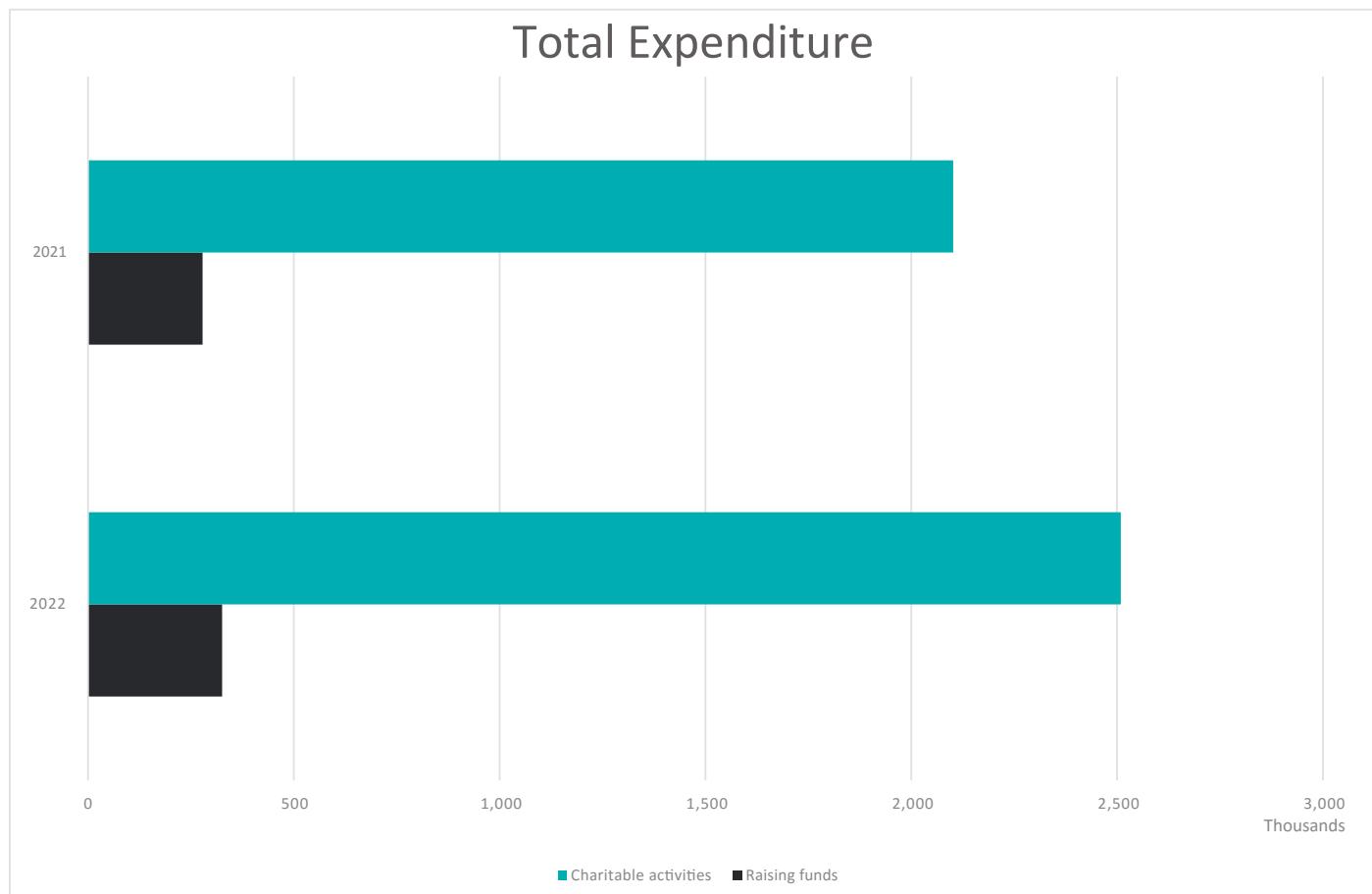
Income from Charitable Activities comes principally from IMNDA's organised campaigns, Drink Tea for MND, Voice 4 MND and Walk While You Can. The digital online platforms for Drink Tea for MND and Voice 4 MND were phenomenally successful in 2021 resulting in the very large incomes we saw in 2021. Now post-Covid, fundraising has moved back offline and as such we see this reflected in the figures.

The remainder of the Income from Charitable Activities comes from Grants from the HSE, Corporates and other Philanthropic organisations. In 2022, this included two grants from The JP McManus Foundation: one for medical equipment and the other for a Nurse. The funding for the Nurse was a total of €500,000 and will fund the Nurses salary and costs for the next five years.

EXPENDITURE

2022 total expenditure was €2,833,408. 89% was charitable activities and 11% was the cost of raising funds.

How Money was Spent

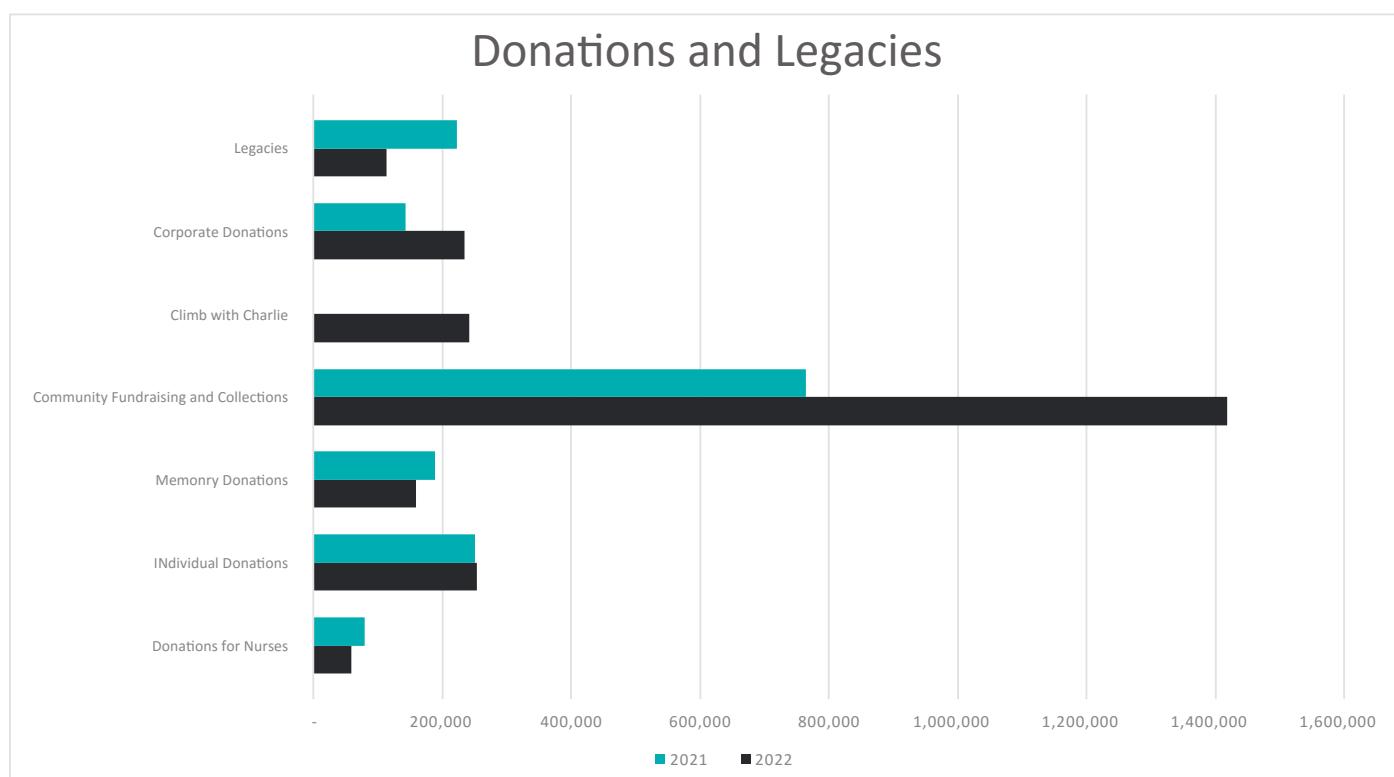


Total Expenditure was €2,833,408 (2021 €2,380,121). €2,508,784 or 89% (2021 €2,101,973 or 88%) was expenditure on Charitable Activities and €324,624 or 11% (2021 €278,148 or 12%) was the cost of raising funds.

The cost of raising funds is a cost that is shown separately to other figures under SORP (FRS102) and at the advice of the Charities Regulator in Ireland. It is a tightly controlled cost and includes all of the costs of raising funds including seeking donations, grants and legacies. It also includes the costs of supporting community fundraising such as sending out tee shirts and buckets.

Community fundraising and taking part in IMNDA fundraising is primarily undertaken by those with MND and their families and friends. IMNDA consider all these events a vital method of maintaining contact with our MND Community.

The cost includes all the direct costs of fundraising, including fundraising salaries, radio adverts, purchasing merchandise etc. It also includes a portion of support costs.



Client and Carer supports include the costs of counselling grants for those with MND and their families, bereavement counselling, the CEO compassionate fund for clients, client advocacy and communication costs and the salaries of non-nursing staff directly providing services to our MND community.

Counselling grants increased 68% in 2022 to €28,527 with clients accessing counselling services in real life. The CEO compassionate fund increased 68% to €12,302 with requests to the end of 2022 to help fund heating client homes. This trend has been seen into early 2023.

In 2022, the board created the post of Community Engagement Manager to ensure effective fostering and maintenance of relationships between IMNDA and international MND associations (in particular England, Wales & Northern Ireland & MND Scotland) for the benefit of MND clients and their families. Community engagement costs are costs related to this post.

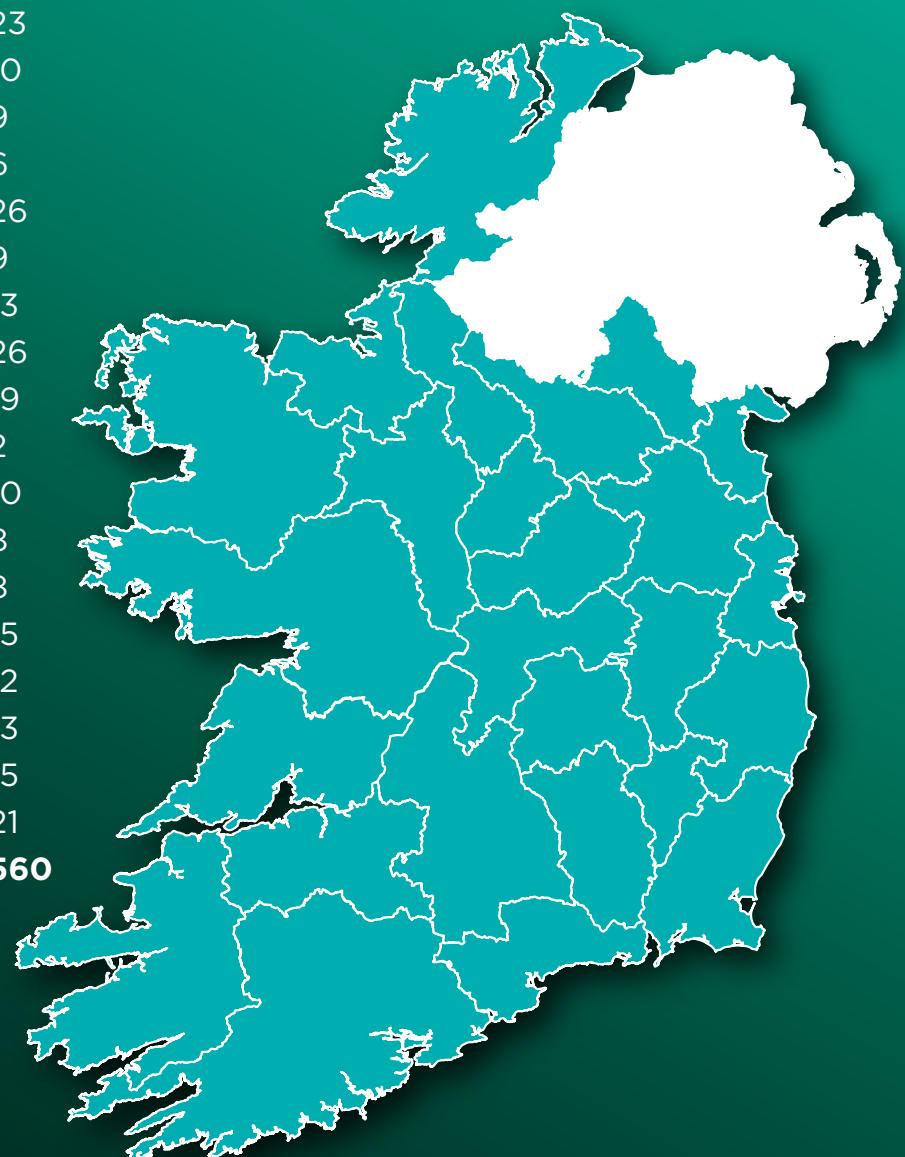


ACHIEVEMENTS & PERFORMANCE – THE IMPACT OF YOUR SUPPORT

In 2022, IMNDA provided services to 560 people across Ireland. There were 191 new registrations to our services and very sadly, we lost 155 people to MND during 2022. This was a 2% increase when compared with 2021.

County	Male	Female	Total
Carlow	1	3	4
Cavan	7	10	17
Clare	6	7	13
Cork	45	22	67
Donegal	15	15	30
Dublin	92	47	139
Galway	12	16	28
Kerry	11	6	17
Kildare	11	12	23
Kilkenny	7	3	10
Laois	8	1	9
Leitrim	3	3	6
Limerick	15	11	26
Longford	5	4	9
Louth	8	5	13
Mayo	15	11	26
Meath	12	7	19
Monaghan	1	1	2
Offaly	8	2	10
Roscommon	4	4	8
Sligo	4	4	8
Tipperary	6	9	15
Waterford	7	5	12
Westmeath	11	2	13
Wexford	10	5	15
Wicklow	11	10	21
Total	335	225	560

“We met angels and helpers in many forms while Dad suffered his illness with dignity. IMNDA were an immeasurable support to us.”



NURSING SERVICE

We ensure that someone with MND and their family always has an expert MND nurse to turn to for practical advice and comfort. Having a nurse to talk to can be the difference between coping and not coping at all.

The support of IMNDA is a very valuable resource. They can supply the equipment I need now and may need in the future. But more importantly for me, the availability of dedicated MND nurses on call should I have any questions or concerns is hugely positive and reassuring.

Continuity of care is crucial when it comes to managing a complex condition such as Motor Neurone Disease. Our MND specialist nurses are central to this service. They act as a link between our clients and families and community healthcare professionals, consultant neurologists and the services team in IMNDA.

There is no one size fits all when it comes to MND so having our nurses out in the community, helping to co-ordinate care for our clients is paramount. They help our clients and carers navigate their way through what is a very complex disease.

The support IMNDA offers is truly sanity saving. They swooped in within two days of me contacting them, a visit from a nurse, within a week. Advice, supports, reassurance and a sense of not being on our own were all invaluable in the midst of shock and grief and this support continues.

Our nurses attend MND hospital clinics, liaise with healthcare professionals such as occupational therapists,

physiotherapists and speech and language therapists and ensure palliative care supports are in place when needed. They help our clients and carers navigate their way through what is a very complex disease.

Upon registering with IMNDA, a newly diagnosed person will receive a first contact call from one of our nurses within seven working days and arrange a first home visit. This nurse will then be their main point of contact for the duration of their illness. Normal nursing service was delivered in 2022 with less need for virtual engagement.

IMNDA nurses carried out 787 home visits to people living with MND. They also met with a further 479 as part of their multi-disciplinary work through clinics. This was a slight decrease on last year due to one staff member leaving and a gap before new staff commenced in role.

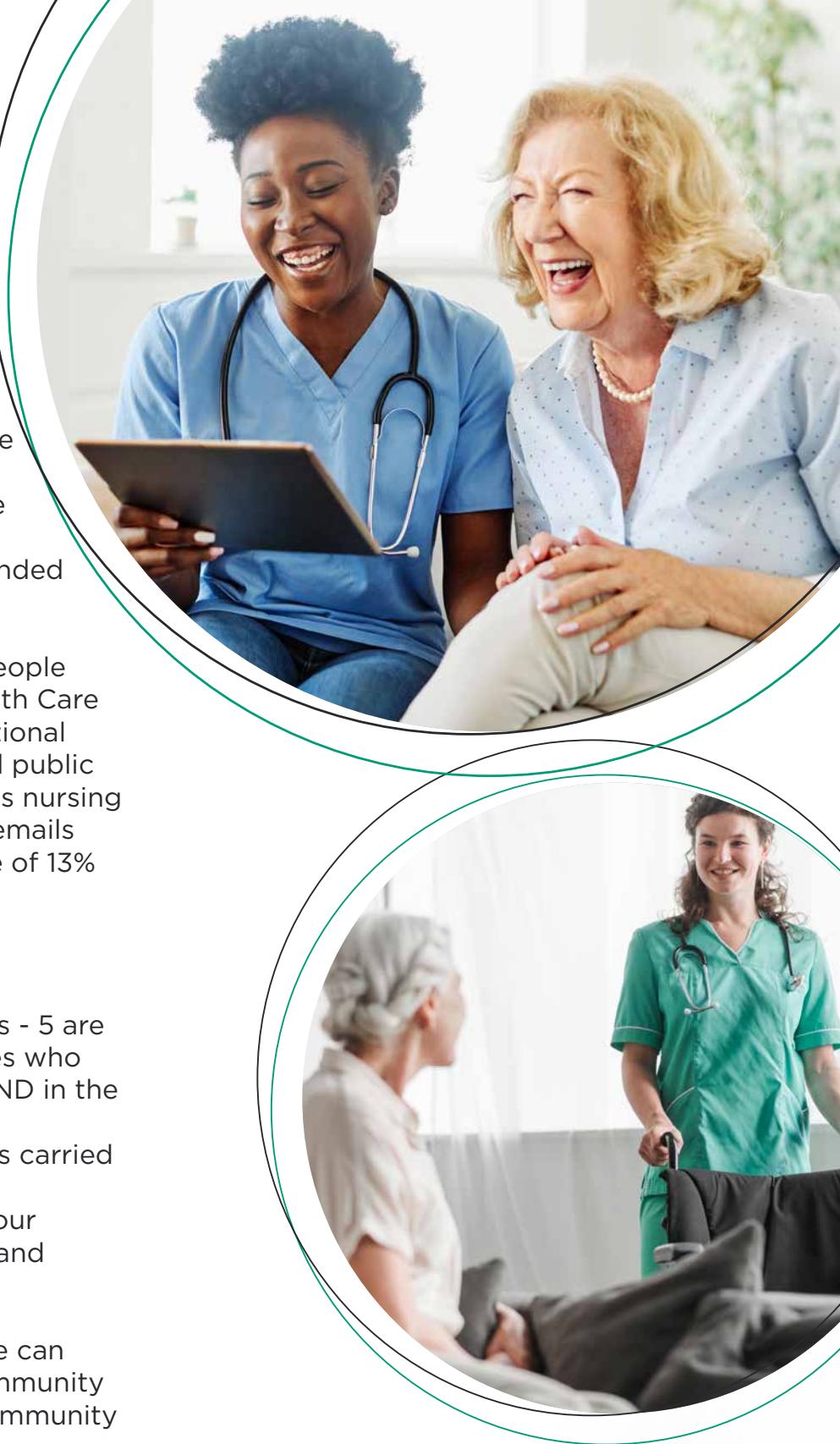
We welcomed Kathryn Foley, our 5th IMNDA nurse, thanks to the extraordinary generosity of the J.P McManus Foundation. Kathryn commenced in October 2022 covering the southwest of the country. We also welcomed Naomi Fitzgibbon, Director of Nursing and Services to the organisation who started in June 2022. This brings our nursing team up to 6 - 1 Nursing Manager and 5 outreach MND Nurses.

The IMNDA nursing team attended 232 multidisciplinary meetings in hospitals and the community. This was an increase on 2021 as services began reopening after COVID. These meetings allowed community healthcare professionals, IMNDA nurses and hospital clinicians to trouble shoot potential issues due to the fragmentation of care in the community as a result of many health care workers being seconded due to the pandemic.

The number of contacts with people living with MND and Allied Health Care Professionals including occupational therapists, physiotherapists and public health nurses accessing IMNDA's nursing service in person via phone or emails amounted to 18,543 an increase of 13% on 2021.

Nursing Highlights:

- IMNDA now employs 6 nurses - 5 are full time MND outreach nurses who care for people living with MND in the community
- In 2022 our 5 outreach nurses carried out 787 home visits
- They engaged virtually with our families through 18,543 calls and emails
- They educate Health Care Professionals so the best care can be provided in their local community and in 2020 attended 232 community meetings
- IMNDA receives no state or HSE funding towards the nursing service, it is funded entirely by public donations and fundraising activities.



EQUIPMENT

We supply specialised equipment as and when it is required and as quickly as possible.

The wheelchair, iPad for communication and the bed provided have made a huge difference to my comfort, mobility and social life.

Ensuring people living with MND remain in their own homes for as long as possible is one of our main priorities. Therefore, having the right equipment, at the right time, is crucial. A powered wheelchair can give someone a new lease of life, allowing them to keep their independence. A communication aid allows them to still be part of the conversation. A stair lift means they can access their entire house and not be confined to one room or one floor. A panic alarm system gives family members some peace of mind.

All simple things that most of us take for granted. Waiting is not an option for equipment when you have a progressive condition like MND.

- In 2022 IMNDA spent €769,593 on the provision, storage, distribution, cleaning and maintenance of specialised aids and appliances for people with MND.

We work as a neuro healthcare specialist to ensure that people living with MND have the most up to date equipment. During the year 315 pieces of new equipment were purchased. The most requested pieces of equipment include but are not limited to: comfort seating, eye gaze communication technology, moto Meds, air mattresses, power wheelchairs and stair lifts. Communication aids continue to be a lifeline for many of our clients with increase in need for Assistive technology, including eye gaze equipment and voice recorders and amplifiers. We introduced the funding of Voice Banking during 2022 which enabled 14 people to save their voice with the Speak Unique application.

The eye gaze system has allowed me to maintain interaction and communication which has contributed greatly to my sense of wellbeing.

Our direct expenditure on equipment in 2022 was €741,000 which we received €16,000 restricted funding from the HSE. Therefore €725,000 was raised directly through donations and fundraising.



HOME CARE GRANT

We support the caregivers who spend their days clothing, feeding and bathing their loved ones. They need a break. Financial assistance towards home care gives caregivers 5 hours a week to take some time for themselves.

IMNDA provides financial assistance towards extra home care hours when there is a shortfall in what is needed versus what the HSE can provide. In 2022, IMNDA spent €328,462 (2021: €382,413) on Home Care Grants. Our families found it extremely difficult to locate suitable carers in their communities which unfortunately reduced our expenditure here.

We received €39,000 restricted funding from the HSE for our home care grant and the remaining money was fundraised by our loyal donors and supporters.

- In 2022, IMNDA spent €328,000 on home care hours
- On average €26 will pay for one hour of home care

The wheelchair, iPad for communication and the bed provided have made a huge difference to my comfort, mobility and social life.



COUNSELLING

We fund counselling sessions for an MND sufferer or their loved one. A diagnosis of MND is a shattering blow and someone affected often needs the opportunity to vent.

“IMNDA immediately provided me with a counsellor to provide emotional support. At every stage of the way, IMNDA have been there providing me with the support I've needed.”

Finding ways to cope following the diagnosis of a fatal illness such as Motor Neurone Disease can be incredibly difficult. It has a huge impact on the entire family and can be a heavy weight to bare. Everyone will process the diagnosis differently and at different stages of their journey. Having access to a qualified counsellor can often be a great source of comfort. So, for those who do want to talk, IMNDA provides funding towards counselling sessions for registered clients and one family member. This funding includes bereavement counselling.

- IMNDA provides funding for counselling sessions to try to alleviate feelings of isolation
- €29,000 was spent on counselling in 2022 which is funded solely through donations and fundraising activities
- On average €60 funds one counselling session
- 124 people accessed this grant which was up over 50% compared with 2021



MND RESEARCH

Our MND Community needs hope. Recognising that today's research could be tomorrow's treatment and cures, IMNDA continues to invest in key research projects, both nationally and internationally, on an annual basis.

In 2021, we committed funds (€50,000 per annum) to Project TRICALS over a further three-year period 2021-2023, a research and treatment project to cure ALS/MND. The aim of this project is to develop a precision medicine-based approach towards new treatments for MND. It is an exciting project which involves ALS/MND centers in Ireland (led by Professor Hardiman and her team), in Holland, the UK, France, Belgium, and Italy.

IMNDA also part funds a Research Fellow post in Trinity College Dublin at a cost of €50,000 per annum with an Associate Professor in ALS/MND Research Methodology and Ethnography.

In 2022, thanks to the tremendous funding received from the Climb with Charlie campaign. We have invested €241,806 from the Climb with Charlie campaign into a Phase 3 trial called Lighthouse II.

This is an experimental study into a new drug Triumeq being run by Research Motor Neurone and other Research

Investigators into the effectiveness of Triumeq, a drug that has been shown to suppress genetic reactivation and may slow disease progression in people living with MND.

As always, the ultimate aim of all projects funded through IMNDA is to improve the lives of people living with MND and their families. Our vision remains a world free of MND and the only way that this vision can be realised is through progress in MND research. We are only able to fund this research because of the money raised nationally by our loyal supporters.



IMNDA CONFERENCE & WEEKEND

Every year we combine our AGM and conference with a very special Patient and Carer weekend away. This has proved to be very beneficial for both clients and families, as well as everyone in IMNDA.

It gives families affected by MND a chance to spend time with other families who are on the same journey. It also gives them greater insights into the latest developments in MND and families hear of developments within the Association.

From an organisational point of view, it provides us with a platform to connect with our service users on a deeper more personal level, which in turn helps us shape and improve our service offering.

In 2022 the conference was held in The Charleville Park Hotel on 6th October. We had a number of speakers covering topics such as:

- Research
- Voice banking
- Modifying food & keeping it tasty

Having seen what can be done with technology in the previous two years, we ran our first hybrid conference event with a Zoom webinar. This allowed those living with MND, their families and healthcare professionals to tune in from living rooms and offices all over the country. It also enabled us to have speakers from the UK, which wouldn't have been possible if they had to physically travel to the conference.



2022 FUNDRAISING HIGHLIGHTS

CLIMB WITH CHARLIE

On 2nd April 2022, Charlie Bird brought the nation with him when he climbed Croagh Patrick to raise funds for IMNDA and Pieta House. Charlie announced he would climb the reek with family and friends, and he encouraged people from all over Ireland to climb their own mountains locally for people with terminal illnesses and mental health issues.

He chose to fundraise for IMNDA as he himself had been diagnosed with MND. He also chose Pieta House as this was a charity he had supported for many years.

Lots of well-known people joined the campaign, from Daniel O'Donnell, Imelda May, Dermot Bannon, Bas Ashmawy, Damien Dempsey, Paddy Moloney, Carl Henry and Johanna Donnelly to name but a few. Bono and U2 donated a song to the campaign and Michael English penned another beautiful song along with a family member from the MND community. Dunnes Stores also got involved with the campaign. They dedicated the whole weekend to Climb with Charlie campaign and asked their customers to make donations at their checkouts.

With the on-going press about the event from January to April, the whole country was brought along on the journey with Charlie, his wife Claire & Tiger the dog. They visited schools up and down the country where songs were sang, dances were danced, instruments were played. Charlie, Claire & Tiger were met with a warm welcome from everyone.

Over €3.3million was raised from the event overall and in July a cheque presentation was made to both IMNDA and Pieta House. From these phenomenal funds, IMNDA established the "Charlie Bird Development Fund" after a national consultation process with our MND community. The overarching objective of the fund is to provide the necessary support to help those with MND live as independent a life as possible in their own home and within their own community. Projects from this fund will include:



- Hiring a 6th Nurse for the midland's region
- Contribute funding towards a clinical research project into improved treatments for MND, overseen by Professor Orla Hardiman, Trinity College, Dublin
- Funding for those living with MND who wish to avail of a voice banking service
- A respite 'recharge' grant for a hotel stay away from home for families in taking a well-deserved break in a comfortable and convenient location.
- A transport grant to enable clients make their MND clinic appointments in comfort
- A care giver respite grant to alleviate the burden of care felt by many

From all in IMNDA we are blown away by the support and generosity of absolutely everyone who got involved with Climb with Charlie. We cannot thank everyone enough – there are simply no words to describe the gratitude, love and appreciation we have for the thousands of people in this great country and around the world that extended the hand of friendship and supported this extraordinary climb. To Charlie, Claire and Tiger – what you have achieved, in such a short period is momentous. We thank you from the bottom of our hearts for your courage, spirit and friendship. To raise that kind of money is almost unfathomable.



COMMUNITY FUNDRAISERS

Aside from Climb with Charlie, 2022 was one of the biggest years for Community fundraising. Over 230 events were ran right across the country – from Donegal to Dublin, Cavan to Cork and Mayo to Monaghan. Every county came out in force to support MND and the work of the association.

A special mention must go to the West of Ireland who not only hosted Charlie's Croagh Patrick Climb but also organised Hurling for Hope which took place in March 2022. A group of friends, players, mentors and teammates from Ballyhaunis GAA Club took on a 100km solo run with a hurling ball from Castlebar to Roscommon. This phenomenal event raised more than €210,000 split between IMNDA and Mayo Roscommon Hospice.

A special mention must also go to some of our incredible families. Thomas Doonan asked the people of Bawnboy to 'Move in March' and they surely did and they didn't stop until they raised €43,000! Also down in Munster we had incredible support in Tipp for Mairead Gill's 'Motor with Mairead' which was another real community effort raising over €70,000.



Community fundraising is the backbone of the association and without the garden parties, walks, runs and cycles we would not be able to support people up and down this country living with MND. Without the community, we would not be able to continue providing care.



ORGANISATION & GOVERNANCE

ROLE OF BOARD

IMNDA has a governing Board of Directors, all of whom are non-executive. The Board each volunteer their time and expertise to bring a combined unique knowledge and skillset to enable our mission of supporting those living with Motor Neurone Disease in Ireland. IMNDA was founded under a Memorandum

of Association, which established the objects and powers of the charitable company and is now governed under its Constitution in accordance with the Companies Act 2014. The Directors and Company Secretary who served during the year did not have a beneficial interest in IMNDA.

GOVERNANCE AND MANAGEMENT

IMNDA is governed by a Board of Directors (all of whom are non-executive). The Directors and Company Secretary who served during the year did not have a beneficial interest in the Company.

The Board comprises of experienced members drawn from a variety of sectors, including nursing, marketing, communications, HR and finance whose skills and expertise help the charity to maximise its potential and who steer the Executive and management team in matters of governance, strategy, and legal.

The Board is also responsible for appointing the Chief Executive Officer

(CEO) and setting pay rates for the CEO and senior staff.

The Board gives their time to IMNDA on a voluntary basis and received no remuneration. Out of pocket expenses may be reimbursed, in accordance with policy.

Following updates to the Companies Act 2014, from 2016 we drew up a new level of service for all members of the board. This means members of the Board may serve a maximum of three three-year terms. This Board rotation ensures that new members are introduced to provide fresh perspectives and skills to the Board.

Board of Directors/ Trustees			
Name	Meeting attended in 2022	Length of service	Profile Summary (see website for further information)
Jonathan Healy (appointed chairperson 7th October 2022)	5/5	7 years	Jonathan Healy is a broadcaster and communications consultant. He established his own communications business in 2017, specialising in media training, corporate content creation and event facilitation.

Dr Declan MacDaid (chairperson; retired 7th October 2022)	4/4	7 years	Derry native, Dr Declan Mac Daid, was educated at St Columb's College, Derry and spent 22 years as a Headmaster in Dublin. He holds several degrees including a Masters in Leadership & Management and a Doctorate in Education specialising in Teaching and Ethics
Katie Hallissey (Company Secretary)	5/5	7 Years	Katie Hallissey hails from Blarney, Cork. She lost her father to MND in 2010 and impressed by the work and support of IMNDA, she has since worked in the southern area of the country, fundraising and raising awareness of the condition.
Alison Gray (Treasurer)	4/5	7 Years	Alison Gray completed her BA in Business Studies for Accounting in Dublin and started her career as a senior auditor. Alison went on to become an Audit Director in BCK after working there since 2007. Alison left BCK in 2019 and is now working in a role as an internal financial controller for Irish SME's
Bernie Connolly	5/5	7 years	Bernie Conolly is a professional advisor in Midwifery & Nursing with Bord Altranais agus Cnáimhseachais na hÉireann. She is a Registered General Nurse and Registered Midwife.
Angela Hogan (Resigned February 2022)	1/1	6 years	Angela Hogan has been working in Human Resources with the Mater Private Hospital since 1996. Her current responsibilities are around Learning and Development for the Mater Private (Dublin and Limerick).
Norman Hughes	5/5	5 years	Norman Hughes is a qualified Financial Advisor and Consultant with more than 20 years' experience within the Financial Services Industry. Norman left his position as Head of Change in Permanent TSB bank to set up his own consultancy practice in 2013.
Joseph Ritchie (Appointed February 2022)	4/5	1 year	Admitted to the role of Solicitors in 1998. Joseph has run his own legal Practice as a sole practitioner since 2005 under the name of Donal M Gahan Ritchie & Company with expertise in property, probate/estate planning and litigation. J
Gillian Lynch (Appointed February 2022)	4/5	1 year	Gillian is a solicitor with more than 20 years' experience. Gillian is currently Knowledge Director in a top-tier law firm where she leads a team of knowledge lawyers and legal librarians. She is responsible for developing and implementing the firm's knowledge strategy.
Lisa Doherty (Appointed February 2022)	5/5	1 year	Lisa Doherty is a public servant with over 25 years' experience in the Education Sector. She completed her Bachelor of Arts Degree in Human Resource Management with the National College of Ireland.

The Management team has been led by Lillian McGovern since June 2021. The team consists of non-clinical management and professional staff working alongside a team of registered nurses who are based regionally. The nursing team delivers IMNDA outreach community service as well as working as part of the overall multi-disciplinary team at each of the MND centers at Beaumont, Cork and Galway.

The CEO and senior management team oversee the day-to-day decision making and the Board is responsible for appraising and monitoring the work of the CEO. The CEO is answerable to the Board through the Chairperson and does not make decisions outside the parameters established by the Board. At each Board meeting the CEO's report gives an overview of finances, operations, HR and staffing, fundraising, services, and strategy implementation. Expenditure is in line with agreed annual budgets and items of expenditure outside



these are brought to the Board for their approval. Likewise, any large items of expenditure by way of capital spend is brought to the Board's attention for their approval.

GOVERNANCE STANDARDS

The Board are committed to maintaining the highest standards of corporate governance and has taken action to ensure we are fully compliant with the principles outlined in the Charities Governance Code as issued by the Charities Regulator of Ireland. IMNDA has registered as a Triple Lock Charity.



Best Practice in Transparency and Accountability

TEAM IMNDA

WE ARE HERE TO MAKE SURE NO-ONE HAS TO FACE MND ALONE

MND is a life-changing illness and we are dedicated to making each change as smooth as possible for all those directly or indirectly living with it. To do this, it takes a committed team of professionals, people who know intimately what our MND community are going through. Our small team of 15 are there to make sure that every call, text, email is answered. We are there every step of the journey. Whether you are from Donegal or Dublin, Cavan or Cork – we are here to support you.

As of the 31 December 2022, IMNDA employed an average of 17 staff members. The average number of full-time employees in the year was 15 and the average number of part-time employees was 2.

The employees were employed in the following activities and in the following salary bands at the year end.

Staff type	Number in 2022	Number in 2021
Fundraising	3	3
Finance and Management	2	2
Advocacy and Communications	2	2
Patient/Client Services Support	3	4
Community Engagement	1	N/A
Nursing Staff	6	4

Salary Bands	Number in 2022	Number in 2021
€50,000 - €59,999	2	5
€60,000 - €69,999	3	0
€70,000 - €79,999	0	0
€80,000 - €89,999	1	1

CEO salary. The CEO earns the highest salary above. They also receive a 5% contribution to their pension scheme. They are provided with a company phone and laptop. Business travel and subsistence are refunded at civil service rates. They do not receive any other benefits.

MEET OUR STAFF



Lillian McGovern
CEO



Naomi Fitzgibbon
Director of Nursing



Tracy Hutchin
Community Engagement
Manager



Johanna McGrath
Information & Support Officer



Paula McNally-Krenn
Services Co-Ordinator



Lisa McNally
Services Administrator



Kathryn Foley
MND Nurse



Fidelma Rutledge
MND Nurse



Louise Hennessy
MND Nurse



Eithne Cawley
MND Nurse



Maire Hayes
MND Nurse



Maria Hill
Head of Compliance &
Finance



Gemma Watts
National Development
Manager



Jackie Martin
Fundraising Executive



Linda Foy
Fundraising Administrator



Maeve Leahy
Head of Communications &
Advocacy



Derbhla Wynne
PR & Communications
Executive

“From personal experience IMNDA are a fantastic team. They work with the family every step of the way; nothing is left undone. They work with you at whatever pace you are at. I will never ever forget the conversations with the IMNDA nurse. The funding for all the equipment and how fast it could be in our home, just unbelievable!”

Until there is a cure, there is care

RELEVANT AUDIT INFORMATION

The Board believe that they have taken all steps necessary to inform themselves of any relevant audit information and have established that the Charity's statutory auditor is aware of that information. In so far as they are aware, there is no relevant audit information of which the Charity's statutory auditors have not been provided.

AUDITOR

The Auditor, Crowleys DFK has agreed to continue in office under Section 383(2) of the Companies Act 2014.

A resolution proposing their reappointment will be put to the Annual General Meeting.

HEALTH & SAFETY

It is the policy of IMNDA to ensure the health and safety of its employees by maintaining a safe place and systems of work.

This policy is based on the requirements of employment legislation, including the Safety, Health and Welfare Act 2005. This policy is routinely updated and reviewed.



Compliance with Sector-Wide Legislation & Standards

- The Companies Act 2014
- The Charities SORP (FRS 102)
- The Charities Governance Code

POST BALANCE SHEET EVENTS

There have been no events after the year-end that require an adjustment to, or additional disclosure in, the Financial Statements.

In 2022, IMNDA received two sizable receipts that have not been fully recognised as income in 2022 – The JP McManus Foundation and the #climbwithcharlie campaign.

The JP McManus Foundation made an award to IMNDA, to the sum of €500,000 to support the provision of an additional nurse and associated costs such as travel expenses, in the mid-west; Limerick, Tipperary, Cork and Kerry. This funding commenced on the 26th of October 2022 and will be spent over the next five years. On 31 December 2022 we had €483,322 left to spend and only €16,678 has been shown as income in these accounts. This has been recognised as other grant income in the Statement of Financial Activities. We will be showing approximately €100,000 as income each year as the money is spent.

We received €1.72 million from the #climbwithcharlie campaign during 2022. In consultation with our members, their families and Charlie Bird we have developed the Charlie Bird Development

Fund. 7 programmes or initiatives have been created under this fund. The monies will fund the below programmes:

- Clinical Nurse Specialist (CNM2) for Midland's region
- Development of a voice banking service grant aided
- Development of a transport support service through MND centers
- Development of a respite "recharge" service
- Development of a Carer Support programme
- Establishment of a dedicated fund for longer-term respite care
- Support for three-year EU Research programme into MND treatments

In the 2022 accounts we have paid in advance €241,806 for MND Treatment Research and recorded €241,806 as income in these accounts. This has been recognised as donations in the Statement of Financial Activities. We have €1.5 million left to spend on the services above over the next few years.

RESERVES POLICY

The Board of IMNDA has set a reserves policy which requires:

- Those reserves are being maintained at a level which ensures that IMNDA core activity could continue during a period of unforeseen difficulty.
- A proportion of reserves are maintained in a readily realisable form.

This takes into account:

- Risks associated with income and expenditure being different from that budgeted.
- Planned activity level and potential opportunities.
- The organisation's contractual commitments.
- The cost associated with potentially having to make staff redundant in an emergency situation.

The level of reserves is kept under constant review through ongoing financial reporting and production of annual audited financial statements.

	Total 2022
	€
Restricted Reserves	
Medical Equipment purchased by funders	33,239
Voice banking purchased by funders	23,296
	56,535
Unrestricted Reserves	
Working Capital Reserve	1,502,627
Lease for Six Years	470,356
Capital Expenditure	501,179
Respite provision project	700,000
Total Unrestricted Reserves	3,174,162
Total Reserves from Balance Sheet	3,230,697

ACCOUNTING RECORDS

The Directors acknowledge their responsibilities, under section 281 to section 285 of the Companies Act 2014, to keep adequate accounting records for the company.

To secure compliance with the requirements of the Act, the finance function has been adequately resourced by means of employing an accountant reporting directly to the CEO and the Finance Committee.

The accounting records of the company are kept at the registered office and principal place of business at Unit 3, Ground Floor, Marshalsea Court, 22/23 Merchant's Quay, Dublin 8.

GEOGRAPHIC AREAS

No income was received from other Geographic Markets and as a result no disclosure is required under the Companies Act 2014, Schedule 3, Part IV 65(2).

PRINCIPAL RISKS AND UNCERTAINTIES

In common with all organisations set up on a non-profit/ charitable basis, the company has uncertain income streams coupled with the increasing wages/supplies costs that face all companies in Ireland. The Directors are satisfied that the risks facing the organisation have been identified and managed through the ongoing maintenance of the Risk Register and the annual 'Risk Assessment Review'.

PAYMENTS OF CREDITORS

The Directors acknowledge their responsibility for ensuring compliance with the provisions of the European Communities (Late Payment in Commercial Transactions) Regulations 2012. It is the organisation's policy to agree payment terms with all suppliers and to adhere to those payment terms.

LOBBYING AND POLITICAL CONTRIBUTIONS

There were no political contributions in 2022 (2021 Nil) and as a result no disclosures are required under the Electoral Act 1997. As required under the Regulation of Lobbying Act 2015, IMNDA records all lobbying activity and communications engaged in with the Designated Public Officials. It has made all the returns and submissions required by the Act. In 2022 we had no such lobbying or communications.

DIRECTORS' RESPONSIBILITIES STATEMENT

The directors are responsible for preparing the financial statements in accordance with applicable Irish law and regulations.

Irish company law requires the directors to prepare financial statements for each financial year. Under the law the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council. Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities, and financial position of the charity as at the financial year end date and of the net income or expenditure of the charity for the financial year and otherwise comply with the Companies Act 2014.

In preparing these financial statements, the directors are required to: select suitable accounting policies and apply them consistently; observe the methods and principles in the Statement of Recommended Practice: Accounting and Reporting by Charities; make judgements and estimates that are reasonable and prudent; state whether the financial statements have been prepared in accordance with the relevant financial reporting framework, identify those standards, and note the effect and the reasons for any material departure from those standards; and prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The directors confirm that they have complied with the above requirements in preparing the financial statements.

The directors are responsible for ensuring that the charity keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the charity, enable at any time the assets, liabilities, financial position and net income or expenditure of the charity to be determined with reasonable accuracy, enable them to ensure that the financial statements and the Directors' Annual Report comply with Companies Act 2014 and enable the financial statements to be audited. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Jonathan's Signature



Alison's Signature



Dated: 8th May 2023

Dated: 8th May 2023

SUMMARY OF FINANCIAL STATEMENTS 2022

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INDEPENDENT AUDITOR'S REPORT

to the Members of The Motor Neurone Disease Association

Report on the audit of the financial statements

Opinion

We have audited the charity financial statements of The Motor Neurone Disease Association for the financial year ended 31 December 2022 which comprise the Statement of Financial Activities (incorporating an Income and Expenditure Account), the Balance Sheet, the Statement of Cash Flows, and the notes to the financial statements, including the summary of significant accounting policies set out in note 2. The financial reporting framework that has been applied in their preparation is Irish law and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with FRS 102.

In our opinion the financial statements:

- give a true and fair view of the assets, liabilities, and financial position of the charity as at 31 December 2022 and of its surplus for the financial year then ended;
- have been properly prepared in accordance with FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland", as applied in accordance with the provisions of the Companies Act 2014 and having regard to the Charities SORP; and
- have been properly prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are described below in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with ethical requirements that are relevant to our audit of financial statements in Ireland, including the Ethical Standard for Auditors (Ireland) issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and the Provisions Available for Audits of Small Entities, in the circumstances set out in note 4 to the financial statements, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other Information

The directors are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our Auditor's Report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2014

In our opinion, based on the work undertaken in the course of the audit, we report that:

- the information given in the Directors' Annual Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- we have obtained all the information and explanations which, to the best of our knowledge and belief, are necessary for the purposes of our audit.

In our opinion the accounting records of the charity were sufficient to permit the financial statements to be readily and properly audited and the financial statements are in agreement with the accounting records.

INDEPENDENT AUDITOR'S REPORT

to the Members of The Motor Neurone Disease Association

Matters on which we are required to report by exception

Based on the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified any material misstatements in the Directors' Annual Report. The Companies Act 2014 requires us to report to you if, in our opinion, the disclosures of directors' remuneration and transactions required by sections 305 to 312 of the Act are not complied with by the company. We have nothing to report in this regard.

Respective responsibilities

Responsibilities of directors for the financial statements

As explained more fully in the Directors' Responsibilities Statement set out on page 37, the directors are responsible for the preparation of the financial statements in accordance with the applicable financial reporting framework that give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the directors are responsible for assessing the charity's ability to continue as a going concern, disclosing, if applicable, matters related to going concern and using the going concern basis of accounting unless management either intends to liquidate the charity or to cease operations, or has no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditor's Report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is contained in the appendix to this report, located at page 42, which is to be read as an integral part of our report.

The purpose of our audit work and to whom we owe our responsibilities

Our report is made solely to the charity's members, as a body, in accordance with Section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the charity's members those matters we are required to state to them in an Auditor's Report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume any responsibility to anyone other than the charity and the charity's members, as a body, for our audit work, for this report, or for the opinions we have formed.

Natalie Kelly
for and on behalf of
CROWLEYS DFK UNLIMITED COMPANY
Chartered Accountants and Statutory Audit Firm
16/17 College Green
Dublin 2

.....

APPENDIX TO THE INDEPENDENT AUDITOR'S REPORT

Further information regarding the scope of our responsibilities as auditor

As part of an audit in accordance with ISAs (Ireland), we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our Auditor's Report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our Auditor's Report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure, and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

STATEMENT OF FINANCIAL ACTIVITIES

(Incorporating an Income and Expenditure Account)
for the financial year ended 31 December 2022

	Notes	Unrestricted Funds 2022	Restricted Funds 2022	Total 2022	Total 2021
		€	€	€	€
Income					
Donations and legacies	5.1	2,165,945	313,414	2,479,359	1,645,373
Charitable activities	5.2	138,080	430,886	568,966	980,276
Other trading activities	5.3	25,151	-	25,151	18,235
Investments	5.4	16,319	-	16,319	-
Other income	5.5	1,000	-	1,000	4,250
Total income		2,346,495	744,300	3,090,795	2,648,134
Expenditure					
Raising funds	6.1	322,267	2,357	324,624	278,148
Charitable activities	6.2	741,413	1,767,371	2,508,784	2,101,973
Total Expenditure		1,063,680	1,769,728	2,833,408	2,380,121
Net income/(expenditure)		1,282,815	(1,025,428)	257,387	268,013
Transfers between funds		(1,076,282)	1,076,282	-	-
Net movement in funds for the financial year		206,533	50,854	257,387	268,013
Reconciliation of funds					
Balances brought forward at 1 January 2022	19	2,967,629	5,681	2,973,310	2,705,297
Balances carried forward at 31 December 2022		3,174,162	56,535	3,230,697	2,973,310

The Statement of Financial Activities includes all gains and losses recognised in the financial year.

BALANCE SHEET

as at 31 December 2022

	Notes	2022 €	2021 €
Fixed Assets			
Tangible assets	14	545,300	494,357
Current Assets			
Debtors	15	141,270	102,490
Cash at bank and in hand		4,665,684	2,578,066
		4,806,954	2,680,556
Creditors: Amounts falling due within one year	16	(659,416)	(201,603)
Net Current Assets		4,147,538	2,478,953
Total Assets less Current Liabilities		4,692,838	2,973,310
Deferred income after one year	17	(1,462,141)	-
Net Assets		3,230,697	2,973,310
Funds			
Restricted funds		56,535	5,681
General fund (unrestricted)		3,174,162	2,967,629
Total funds	19	3,230,697	2,973,310

Approved by the Board of Directors on 8th May 2023 and signed on its behalf by:



Jonathan Healy



Alison Gray

STATEMENT OF CASH FLOWS

for the financial year ended 31 December 2022

	Notes	2022 €	2021 €
Cash flows from operating activities			
Net movement in funds		241,068	268,013
Adjustments for:			
Depreciation		332,577	351,456
Gains and losses on disposal of fixed assets		20,653	4,020
		594,298	623,489
Movements in working capital:			
Movement in debtors		(38,780)	21,288
Movement in creditors		457,813	(57,484)
Cash generated from operations		1,013,331	587,293
Cash flows from investing activities			
Receipts from investments		16,319	-
Payments to acquire tangible assets		(404,173)	(380,800)
Receipts from sales of tangible assets		(20,653)	(4,020)
Receipts from sales of tangible assets		20,653	3,803
Net cash generated from investment activities		(387,854)	(381,017)
Cash flows from financing activities			
Grants receivable		1,462,141	(44,709)
Net increase/(decrease) in cash and cash equivalents		2,087,618	161,567
Cash and cash equivalents at 1 January 2022		2,578,066	2,416,499
Cash and cash equivalents at 31 December 2022	23	4,665,684	2,578,066

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

1. GENERAL INFORMATION

The Motor Neurone Disease Association is a company limited by guarantee (registered under Part 18 of the Companies Act 2014) incorporated and registered in the Republic of Ireland (CRO Number: 112855). The registered office of the organisation is Unit 3 Ground Floor, Marshalsea Court, 22/23 Merchant's Quay, Dublin 8, D08 C6XP which is also the principal place of business of the organisation. The financial statements have been presented in Euro (€) which is also the functional currency of the organisation.

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

The following accounting policies have been applied consistently in dealing with items which are considered material in relation to the charity's financial statements.

Basis of preparation

The financial statements have been prepared under the historical cost convention, modified to include certain items at fair value. The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland FRS 102".

The charity has applied the Charities SORP on a voluntary basis as its application is not a requirement of the current regulations for charities registered in the Republic of Ireland.

As permitted by the Companies Act 2014, the charity has varied the standard formats in that act for the Statement of Financial Activities and the Balance Sheet. Departures from the standard formats, as outlined in the Companies Act 2014, are to comply with the requirements of the Charities SORP and are in compliance with section 4.7, 10.6 and 15.2 of that SORP.

Fund accounting

The following are operated by the Charity:

Restricted funds

Restricted funds represent grants, donations and sponsorships received which can only be used for particular purposes specified by the donors or sponsorship programmes binding on the directors/trustees. Such purposes are within the overall aims of the charity.

Unrestricted funds

Unrestricted funds include general funds and designated funds, and it represents amounts which are expendable at the discretion of the Directors in furtherance of the objectives of the charity and which have not been designated for other purposes. Such funds may be held in order to finance working capital or capital expenditure.

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

Income

All incoming resources are included in the Statement of Financial Activities when the charity is legally entitled to the income, the amount can be quantified with reasonable accuracy, and it is probable the income will be received. The following specific policies are applied to particular categories of income:

- Voluntary income is received by way of grants, donations and gifts and is included in full in the Statement of Financial Activities when receivable.

- Income from government and other grants, whether 'capital' or 'revenue grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received, and the amount can be measured reliably. Grants, where entitlement is not conditional on the delivery of a specific performance by the charity is recognised within income from donations and legacies. Grants, where related to performance and specific deliverables, are accounted for as the charity earns the right to consideration by its performance and included within income from charitable activities.

- Donated services and facilities are included at the fair value to the charity where this can be quantified. Donations in kind are included at their estimated value to the association in both revenue and expenditure in the year of receipt. Donated facilities are included as both income and expenses at the value to the charity where this can be quantified, and a third party is bearing the cost. Where it is not practicable to measure the value of the resource with sufficient reliability the income is included in the financial period when the resource is sold. An asset is recognised only when those services are used for the production of an asset and the services received will be capitalised as part of the cost of an asset. Where it cannot be quantified the value is recognised when sold. The value of services provided by volunteers has not been included in these accounts. Resources received from non-exchange transactions for which the entity has benefited include:

- Volunteer services

- Revenue from the provision of services is recognised in the accounting period in which the services are rendered

- Deferred income is released to the statement of financial activities when conditions of the funding are met.

Expenditure

Expenditure is recognised on an accruals basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates:

- Costs of raising funds comprise the costs associated with attracting voluntary income, and includes staff and related costs, costs of fundraising and an allocation of support and management costs.

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees, costs of legal advice for trustees and costs linked to the strategic management of the charity including the cost of trustee meetings.

- All costs are allocated between the expenditure categories of the Statement of Financial Activities on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2021

continued

Employee Benefits

The organisation provides a range of benefits to employees, including annual discretionary Christmas bonuses, paid holiday arrangements and defined contribution pension plans.

Short term benefits

Short term benefits, including holiday pay and other similar non-monetary benefits, are recognised as an expense in the period in which the service is received.

Defined contribution pension plans.

The organisation operates a defined contribution plan. A defined contribution plan is a pension plan under which the organisation pays fixed contributions into a separate fund. Under defined contribution plans, the organisation has no legal or constructive obligations to pay further contributions if the fund does not hold sufficient assets to pay all employees the benefits relating to employee service in the current and prior periods.

For defined contribution plans, the organisation pays contributions to privately administered pension plans on a contractual or voluntary basis. The organisation has no further payment obligations once the contributions have been paid. The contributions are recognised as employee benefit expense when they are due. Prepaid contributions are recognised as an asset to the extent that a cash refund or a reduction in the future payments is available.

Tangible fixed assets and depreciation

Tangible fixed assets are recorded at historical cost or deemed cost, less accumulated depreciation (and impairment losses if applicable). Cost includes prime cost, overheads and interest incurred in financing the construction of tangible fixed assets. Capitalisation of interest ceases when the asset is brought into use.

Medical Equipment

All Equipment is capitalised at cost. It is the organisation's policy to capitalise all items which have a unit cost greater than one thousand euros (€1,000). Items purchased with a value or cost less than one thousand euros (€1,000) will be expensed in the period purchased.

Tangible fixed assets are stated at cost or at valuation, less accumulated depreciation. The charge to depreciation is calculated to write off the original cost or valuation of tangible fixed assets, less their estimated residual value, over their expected useful lives as follows:

Medical Equipment	-	33.33% Straight line
Fixtures, fittings and equipment	-	20% Straight line

Debtors

Debtors are recognised initially at transaction price. Subsequently these are measured at amortised cost less any provision for impairment. A provision for impairment of trade receivables is established when there is objective evidence that the organisation will not be able to collect all amounts due according to the original terms of receivables. The amount of the provision is the difference between the asset's carrying amount and the present value of estimated future cash flows, discounted at the effective interest rate. All movements in the level of provision required are recognised in the statement of financial activities.

Creditors

Creditors are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade payables are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Cash and cash equivalents

Cash and cash equivalents include cash on hand, demand deposits and other short term highly liquid investments with original maturities of three months or less. Bank overdrafts are shown within borrowings in current liabilities on the statement of financial position.

Taxation

No charge to current or deferred taxation arises as the charity has been granted charitable status under Sections 207 and 208 of the Taxes Consolidation Act 1997, Charity No CHY 8510. The charity is eligible under the "Scheme of Tax Relief for Donations to Eligible Charities and Approved Bodies under Section 848A Taxes Consolidation Act, 1997" therefore income tax refunds arising from sponsorships exceeding €250 per annum are included in unrestricted funds. Irrecoverable value added tax is expended as incurred.

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2021

continued

Financial Instruments

Debt instruments (other than those wholly repayable or receivable within one year), including loans and other accounts receivable and payable, are initially measured at present value of the future cash flows and subsequently at amortised cost using the effective interest method. Debt instruments that are payable or receivable within one year, typically debtors and creditors, are measured, initially and subsequently, at the undiscounted amount of the cash or other consideration expected to be paid or received. However, if the arrangements of a short-term instrument constitute a financing transaction, like the payment of a debt deferred beyond normal business terms or financed at a rate of interest that is not a market rate or in the case of an out-right short-term loan not at market rate, the financial asset or liability is measured, initially, at the present value of the future cash flow discounted at a market rate of interest for a similar debt instrument and subsequently at amortised cost.

Financial assets that are measured at cost and amortised cost are assessed at the end of each reporting period for objective evidence of impairment. If objective evidence of impairment is found, an impairment loss is recognised in the Statement of Financial Activities.

For financial assets measured at amortised cost, the impairment loss is measured as the difference between an asset's carrying amount and the present value of estimated cash flows discounted at the asset's original effective interest rate. If a financial asset has a variable interest rate, the discount rate for measuring any impairment loss is the current effective interest rate determined under the contract.

For financial assets measured at cost less impairment, the impairment loss is measured as the difference between an asset's carrying amount and best estimate of the recoverable amount, which is an approximation of the amount that the charity would receive for the asset if it were to be sold at the balance sheet date.

3. SIGNIFICANT ACCOUNTING JUDGEMENTS AND KEY SOURCES OF ESTIMATION UNCERTAINTY

The preparation of these financial statements requires management to make judgements, estimates and assumptions that affect the application of policies and reported amounts of assets and liabilities, income, and expenses.

Judgements and estimates are continually evaluated and are based on historical experiences and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

Accounting for depreciation

The organisation provides for depreciation on its tangible fixed assets. Tangible fixed assets are stated at cost or at valuation, less accumulated depreciation. The charge to depreciation is calculated to write off the original cost or valuation of tangible fixed assets, less their estimated residual value, over their expected useful lives. The trustees review on an on-going basis the charge to depreciation to ensure it is consistent with the expected residual value applicable to the different categories of tangibles. The total amount of assets subject to depreciation is €545,300 (2021: €494,357).

Useful Lives of Tangible Fixed Assets

Long-lived assets, consisting primarily of medical equipment, comprise a significant portion of the total assets. The annual depreciation charge depends primarily on the estimated useful economic lives of each type of asset and estimates of residual values. The directors regularly review these asset useful economic lives and change them as necessary to reflect current thinking on remaining lives in light of prospective economic utilisation and physical condition of the assets concerned. Changes in asset useful lives can have a significant impact on depreciation and amortisation charges for the period. Detail of the useful economic lives is included in the accounting policies.

Going concern

At the time of approving the financial statements, the directors have a reasonable expectation that the organisation has adequate resources to continue in operational existence for the foreseeable future. Thus, the Charity continue to adopt the going concern basis of accounting in preparing the financial statements.

4. PROVISIONS AVAILABLE FOR AUDITS OF SMALL ENTITIES

In common with many other charitable companies of our size and nature, we use our auditors to assist with the preparation of the financial statements and to prepare and submit returns to the Companies Registration Office.

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

5.	INCOME	Unrestricted Funds	Restricted Funds	2022	2021
5.1	DONATIONS AND LEGACIES	€	€	€	€
	Corporate Donations	234,754	-	234,754	142,144
	General Donations	1,817,891	313,414	2,131,305	1,281,329
	Wills & Bequests	113,300	-	113,300	221,900
		<u>2,165,945</u>	<u>313,414</u>	<u>2,479,359</u>	<u>1,645,373</u>
5.2	CHARITABLE ACTIVITIES	Unrestricted Funds	Restricted Funds	2022	2021
		€	€	€	€
	HSE Income	-	268,623	268,623	330,590
	Fundraising Events	138,080	-	138,080	555,552
	Government Subsidy Schemes	-	-	-	54,600
	Other Grants	-	162,263	162,263	39,534
		<u>138,080</u>	<u>430,886</u>	<u>568,966</u>	<u>980,276</u>
5.3	OTHER TRADING ACTIVITIES	Unrestricted Funds	Restricted Funds	2022	2021
		€	€	€	€
	Other trading activities	25,151	-	25,151	18,235
5.4	INVESTMENTS	Unrestricted Funds	Restricted Funds	2022	2021
		€	€	€	€
	Investments	16,319	-	16,319	-
5.5	OTHER INCOME	Unrestricted Funds	Restricted Funds	2022	2021
		€	€	€	€
	Other income	1,000	-	1,000	4,250

The total of the income derived by the charity relates from its activities in the Republic of Ireland.

6.	EXPENDITURE RAISING FUNDS	Direct Costs	Other Costs	Support Costs	2022	2021
6.1		€	€	€	€	€
	Raising funds	238,204	-	86,420	324,624	278,148

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

6.2 CHARITABLE ACTIVITIES	Direct Costs	Other Costs	Support Costs	2022	2021
	€	€	€	€	€
Community Engagement	62,088	-	28,808	90,896	-
Home Care	328,462	-	28,808	357,270	428,216
Specialist Medical Equipment	740,785	-	28,808	769,593	738,749
Client Support Costs	304,735	-	79,216	383,951	334,434
Research	341,806	-	-	341,806	101,441
Nursing Services	392,431	-	172,837	565,268	499,133
	2,170,307	-	338,477	2,508,784	2,101,973
	=====	=====	=====	=====	=====

7. ANALYSIS OF SUPPORT COSTS

	2022	2021
	€	€
Support	424,897	480,929
	=====	=====
8. NET INCOME	2022	2021
	€	€
Net Income is stated after charging/(crediting):		
Depreciation of tangible assets	332,577	351,456
Auditor's remuneration: - audit services	11,383	9,861
	=====	=====

9. EMPLOYEES AND REMUNERATION

Number of employees

The average number of full-time employees in the year was 15 and the average number of part time employees was 1. The number employees at the year-end were as follows:

	2022 Number	2021 Number
Fundraising	3	3
Finance & Management	2	2
Client Services Support	3	4
Nursing Staff	6	4
Advocacy & Communications	2	2
Community Engagement	1	-
	17	15
=====	=====	=====

The staff costs comprise:

	2022	2021
	€	€
Wages and salaries	774,637	640,600
Redundancy costs	-	21,874
Social security costs	84,257	57,856
Pension costs	31,431	29,413
	=====	=====
	890,325	749,743
	=====	=====

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

10. SALARY BANDS

There were 7 employees (2021: 5) whose total employee benefits (excluding employer PRSI and pension costs) at the year-end fell within the below categories

	2022 €	2021 €
€50,000 - €60,000	3	5
€60,001 - €70,000	3	-
€70,001 - €80,000	-	-
€80,001 - €90,000	1	-
	<hr/> 7	<hr/> 5
	<hr/> <hr/>	<hr/> <hr/>

CEO salary. The CEO earns the highest salary above. They also receive a 5% contribution to their pension scheme. They are provided with a company phone and laptop. Business travel and subsistence are refunded at civil service rates. They do not receive any other benefits.

Employers' contribution to employers PRSI vary depending on employee circumstances.

All employees (including the CEO) receive a 5% contribution to pension.

Travel and Subsistence rates for all staff (including the CEO) are as outlined by the Revenue Commissioners.

No Directors are remunerated for their role on the Board.

11. KEY MANAGEMENT COMPENSATION

Key management includes the Board of Directors (Executive and non-executive) and all members of the Management. The compensation paid or payable to key management for employee services is shown below:

	2022 €	2021 €
Salaries and other short-term benefits	<hr/> 322,872	<hr/> 226,811
	<hr/> <hr/>	<hr/> <hr/>

The above related to several employees, whose work is primarily client facing. No employees were remunerated over €85,000.

12. RETIREMENT BENEFITS

The organisation operates a PRSA scheme for the benefit of its employees. Contributions payable are charged to the income and expenditure account as the expenditure is incurred.

	2022 €	2021 €
Retirement benefits	<hr/> 31,431	<hr/> 29,413
	<hr/> <hr/>	<hr/> <hr/>

13. RELATED PARTY TRANSACTIONS

Our Directors are Charity Trustees and as such may not profit from carrying out their duties as a Charity Trustee. They do not receive a salary specifically for acting as a Charity Trustee or receive other benefits. However, they may be reimbursed for reasonable expenses, which they incurred directly in carrying out their duties.

In 2022, expenses paid to directors was €Nil (2021: €Nil).

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

14. TANGIBLE FIXED ASSETS

	Medical Equipment	Fixtures, fittings and equipment	Total
	€	€	€
Cost			
At 1 January 2022	2,345,421	90,988	2,436,409
Additions	395,320	8,853	404,173
Disposals	(117,851)	(6,240)	(124,091)
At 31 December 2022	<u>2,622,890</u>	<u>93,601</u>	<u>2,716,491</u>
Depreciation			
At 1 January 2022	1,866,264	75,788	1,942,052
Charge for the financial year	325,542	7,035	332,577
On disposals	(97,615)	(5,823)	(103,438)
At 31 December 2022	<u>2,094,191</u>	<u>77,000</u>	<u>2,171,191</u>
Net book value			
At 31 December 2022	<u>528,699</u>	<u>16,601</u>	<u>545,300</u>
At 31 December 2021	<u>479,157</u>	<u>15,200</u>	<u>494,357</u>

15. DEBTORS

	2022	2021
	€	€
Other debtors	31,158	26,112
Taxation and social security costs	61,181	32,466
Prepayments	48,931	43,912
	<u>141,270</u>	<u>102,490</u>

16. CREDITORS

Amounts falling due within one year

	2022	2021
	€	€
Trade creditors	117,908	98,285
Taxation and social security costs	26,383	36,020
Other creditors	621	1,166
Accruals	12,697	10,084
Deferred income (Note 17)	1,963,948	56,048
	<u>2,121,557</u>	<u>201,603</u>

The Motor Neurone Disease Association is compliant with the relevant tax circulars including circular 44/2006 "Tax Clearance Procedures, Grants, Subsidies and Similar Payments".

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

17. DEFERRED INCOME	2022	2021
	€	€
Within One Year		
Deferred Income	501,806	56,048
After One Year		
At 1 January 2022	-	44,709
Increase / (Decrease) in financial year	1,462,141	(44,709)
At 31 December 2022	1,462,141	-

In 2022, IMNDA received two sizable receipts that have not been fully recognised as income in 2022 – The JP McManus Foundation and the #climbwithcharlie campaign.

The JP McManus Foundation made an award to IMNDA, to the sum of €500,000 to support of the provision an additional nurse and associated costs such as travel expenses, in the mid-west; Limerick, Tipperary, Cork and Kerry. This funding commenced on the 26th October 2022 and will be spent over the next five years. At 31 December 2022 we had €483,322 left to spend and only €16,678 has been shown as income in these accounts. This has been recognised as other grant income in the Statement of Financial Activities. We will be showing approximately €100,000 as income each year as the money is spent.

We received €1.72 million from the #climbwithcharlie campaign during 2022. In consultation with our members, their families and Charlie Bird we have developed the Charlie Bird Development Fund. 7 programmes or initiatives have been created under this fund. The monies will fund the below programmes:

- Clinical Nurse Specialist (CNM2) for Midlands region,
- Development of a voice banking service grant aide,
- Development of a transport support service through MND centres,
- Development of a respite "recharge" service,
- Development of a Carer Support programme
- Establishment of a dedicated fund for longer-term respite care, an
- Support for three year EU Research programme into MND treatments.

In the 2022 accounts we have paid in advance €241,806 for MND Treatment Research and recorded €241,806 as income in these accounts. This has been recognised as donations in the Statement of Financial Activities. We have €1.5 million left to spend on the services above over the next few years.

18. RESERVES

	2022	2021
	€	€
At 1 January 2022	2,973,310	2,705,297
Surplus for the financial year	257,387	268,013
At 31 December 2022	3,230,697	2,973,310

19. FUNDS

19.1 RECONCILIATION OF MOVEMENT IN FUNDS	Unrestricted Funds	Restricted Funds	Total Funds
	€	€	€
At 1 January 2021	2,700,134	5,163	2,705,297
Movement during the financial year	267,495	518	268,013
At 31 December 2021	2,967,629	5,681	2,973,310
Movement during the financial year	206,533	50,854	257,387
At 31 December 2022	3,174,162	56,535	3,230,697

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

19.2 ANALYSIS OF MOVEMENTS ON FUNDS

	Balance 1 January 2022 €	Income €	Expenditure €	Transfers between funds €	Balance 31 December 2022 €
Restricted funds					
Restricted	5,681	744,300	1,769,728	1,076,282	56,535
Unrestricted funds					
Unrestricted General	2,967,629	2,346,495	1,063,680	(1,076,282)	3,174,162
Total funds	2,973,310	3,090,795	2,833,408	-	3,230,697

19.3 ANALYSIS OF NET ASSETS BY FUND

	Fixed assets - charity use €	Current assets €	Current liabilities €	Total €
Restricted trust funds	-	56,535	-	56,535
Unrestricted general funds	545,300	4,756,094	(2,121,557)	3,174,162
	545,300	4,806,954	(2,121,557)	3,230,697

20. STATUS

The liability of the members is limited.

Every member of the organisation undertakes to contribute to the assets of the organisation in the event of its being wound up while they are members, or within one year thereafter, for the payment of the debts and liabilities of the organisation contracted before they ceased to be members, and the costs, charges, and expenses of winding up, and for the adjustment of the rights of the contributors among themselves, such amount as may be required, not exceeding €2.

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

21. GOVERNMENT GRANTS

In accordance with Department of Public Expenditure and Reform Circular 13/2014, the following details the core grants of the organisation applicable to 2022.

Income from government grants comprise of:

Grants made by the HSE (see breakdown below) a to fund the provision of specific charity services to those with motor neurone disease. The amount of such grants received in the year amounted to €268,623 (2021: €330,590). Amounts due at the year-end were €Nil (2021: €Nil). Amounts deferred at the year-end were €Nil (2021: €1,793)

Agency	Type	Restricted	Grant Approved	SoFA	Received 2022	Due / Deferred
HSE	Revenue	Yes	214,037	214,037	214,037	-
HSE	Lottery/Respite	Yes	39,000	39,000	39,000	-
HSE	Lottery/Equipment	Yes	15,586	15,586	15,586	-
			268,623	268,623	268,623	-
			<u>268,623</u>	<u>268,623</u>	<u>268,623</u>	<u>-</u>

Year ended 31 December 2021

Agency	Type	Restricted	Grant Approved	SoFA	Received 2021	Due / Deferred
HSE	Revenue	Yes	214,037	214,037	214,037	-
HSE	Community	Yes	16,000	16,000	16,000	-
HSE	Lottery/Respite	Yes	54,231	54,231	54,231	-
HSE	Lottery/Equipment	Yes	46,322	45,529	46,322	1,793
			330,590	328,797	330,590	1,793
			<u>330,590</u>	<u>328,797</u>	<u>330,590</u>	<u>1,793</u>

The above 2022 grants were rewarded by the following HSE funding locations:

Agency	Type	CHO	Amount
HSE	Revenue	CHO09	214,037
HSE	Lottery/Respite	CHO02	9,000
HSE	Lottery/Respite	CHO03	1,000
HSE	Lottery/Respite	CHO05	10,000
HSE	Lottery/Respite	CHO06	10,000
HSE	Lottery/Respite	CHO07	4,000
HSE	Lottery/Respite	CHO08	5,000
HSE	Lottery/Equipment	CHO03	1,000
HSE	Lottery/Equipment	CHO06	8,586
HSE	Lottery/Respite	CHO07	6,000
			268,623
			<u>268,623</u>

22. CONTINGENT LIABILITIES

The organisation had no material contingent liabilities for the year ended 31 December 2022.

23. CASH AND CASH EQUIVALENTS

2022
€

Cash and bank balances **4,665,684**

4,665,684 **2,578,066**

24. POST-BALANCE SHEET EVENTS

There have been no circumstances or events subsequent to the year end, which require adjustment to, or disclosure in the financial statements.

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2022

continued

25. FINANCIAL COMMITMENTS

At the end of 2022, the organisation occupies Unit 3, Ground Floor, Marshalsea Court, 22/23 Merchant's Quay, Dublin 8. The Lease costs are €78,393 per annum. The organisation operated under a 10 year lease term which commenced in January 2020. This lease has a no break clause and a 5-year cap on the rental amount.

	2022 €	2021 €
Payable within one year	78,393	78,393
Payable within two to five years	313,571	313,571
Payable after five years	156,786	235,179
	<hr/> 548,750	<hr/> 627,143
	<hr/> <hr/>	<hr/> <hr/>

26. CONTRIBUTION TO UNPAID VOLUNTEERS

The Trustees are very grateful to the unpaid dedicated volunteers who are vital to the IMNDA's on-going work. Approximately 250 members of the public give their time to assist our fundraising work in all areas including campaigns, events, and administration. Volunteers generously act as Ambassadors representing the IMNDA at various community fundraising events across the country as well as at our own annual calendar of events such as walks and collections which could not go ahead without these committed cohort of helpers.

The IMNDA acknowledges with immense gratitude, the hard work, dedication, care, and attention given by our supporters.

27. APPROVAL OF FINANCIAL STATEMENTS

The financial statements were approved and authorised for issue by the Board of Directors on 8th May 2023.

SUPPLEMENTARY INFORMATION RELATING TO THE FINANCIAL STATEMENTS

**For the Financial Year
Ended 31 December 2022**

Not covered by the report of the auditors

INCOME AND EXPENDITURE

for the financial year ended 31 December 2022

	2022	2021
	€	€
Income		
Government Grants and Revenue Refunds		
HSE Lottery Equipment Grant	15,586	46,332
HSE Lottery Respite Grant	39,000	54,231
Restricted Grant Income- other	-	16,000
HSE Grant in Aid	6,185	6,185
HSE GAA	207,852	207,852
Government Subsidy	-	54,600
Tax Relief and VAT Compensation Scheme	9,214	5,843
	<hr/>	<hr/>
Public and Statutory Funding	277,837	391,033
Donations and Fundraising		
Restricted Nurse Fund Donations	265	922
Direct Mail Nurse Campaign	3,686	3,881
Restricted Personal Donations	13,020	9,670
Drink Tea for MND	69,518	206,932
Unrestricted Charity of the Year Income	9,403	3,084
Corporate Events	10,637	8,008
Unrestricted Corporate Donations	214,714	131,052
Memory Donations	145,305	170,761
Memory Tree	14,029	17,237
Wedding Favours	5,394	2,752
Church Gate Collections	424	-
Collection Boxes	1,378	723
Membership Income	100	220
Individual Donations - Standing Orders	37,110	26,293
Individual Donations - Once Off	194,350	208,464
Benefit Nights	47,158	201
Raffles	2,735	4,244
Sponsored Silence	28,260	156,686
Easter Egg Raffle	-	490
Christmas Fundraising	16,664	14,871
Merchandise Sales	3,093	792
Other Fundraising Events	339,588	153,898
Dublin Marathon	63,611	1,544
Women's Mini Marathon	31,619	10,846
Cycling Events	129,127	94,136
Boxing fundraisers	-	3,435
Walk While You Can	40,302	146,775
Absailing Fundraisers	482	44,669
Golf Classics	31,612	74,045
Skydive	3,003	17,478
Other Active Events	766,886	403,000
RTE Does Comic Relief	378	14,534
Arthur Cox – The Loretto Dempsey Placement	25,000	25,000
Wills & Bequests	113,300	221,900
JP Mc Manus Equipment Grant	40,000	-
Monkstown Hospital Grant	7,500	-
Charities Aid - Voice Banking	30,324	-
AIB Fund - Voice Banking	6,500	-
Hospital Saturday fund	3,000	-
Donegal Business Network Campaign	3,470	-
Bon Secours Limerick Grant	1,000	-
Wyeths Christmas Charity	1,000	-
Irish A.N.T.S Ltd Equipment	27,413	-
The JP McManus Foundation	16,678	-
Climb With Charlie	241,806	-
	<hr/>	<hr/>
Fundraised Incomes	2,741,022	2,178,365

INCOME AND EXPENDITURE

for the financial year ended 31 December 2022

continued

	2022 €	2021 €
Non Cash Incomes		
Donations -in-Kind	-	-
Non Cash Incomes	-	-
Income deferred from previous years		
WWYC Deferred Income	54,617	74,488
Income deferred from previous years	54,617	74,488
Other Incomes		
Investment Income	16,319	-
Other Income	1,000	4,250
Other Incomes	17,319	4,250
Total Income	<u><u>3,090,795</u></u>	<u><u>2,648,136</u></u>

INCOME AND EXPENDITURE

for the financial year ended 31 December 2022

continued

	2022 €	2021 €
Client Service Costs		
Home Help Grant	328,462	382,412
Client Wellbeing (counselling)	28,527	16,610
Annual Memorial Service	9,799	4,894
Patient & Carer Weekend	26,479	-
Other Services Costs	5,555	1,659
COVID19 Support Costs	-	316
CEO Compassionate Fund	12,302	7,329
Community Hub	378	4,674
Medical Equipment Purchases under €1,000	146,914	165,549
Medical Equipment Purchases over €1,000 depreciation	325,542	345,867
Medical Equipment Storage & Transport	49,500	43,629
Medical Equipment Costs	198,592	133,880
Loss on disposal of Medical Equipment	20,653	4,020
	<hr/>	<hr/>
	1,152,703	1,110,839
Research Costs		
Medical Research Costs	341,806	101,441
Fundraising Costs		
Fundraising Printing & Materials	4,914	5,546
Fundraising Advertising	-	37
Fundraising & PR Misc. Costs	7,570	545
Direct Mail Costs	-	165
General Community Fund Raising Costs	382	418
Campaigns Costs - General	2,451	2,184
Drink Tea Costs	24,729	19,340
Sponsored Silence Costs	3,002	3,980
Memory Tree Costs	-	1,358
Easter Egg Raffle	3,444	-
Walk While You Can costs	5,803	1,856
Abseiling costs	-	5,355
Women's Mini Marathon	128	-
A Long Shot	150	836
Climb With Charlie Costs	3,957	-
Individual Giving Costs	-	-
Corporate Fundraising Costs	8,180	2,615
Merchandise Costs (for Resale)	8,926	3,625
Wedding Favours Costs	1,100	-
Memorial Website	-	624
Legacy Costs	3,661	4,350
Christmas Card Costs	456	4,396
	<hr/>	<hr/>
	78,853	57,230

INCOME AND EXPENDITURE

for the financial year ended 31 December 2022

continued

	2022 €	2021 €
Pay Costs		
Gross salaries	748,158	640,598
Employer's NI/PRSI contributions	84,257	57,855
Employer's Pension contributions	31,431	29,412
Redundancy Payments	-	21,876
	<hr/> 863,846	749,741
Non-Pay Costs		
Newsletter Costs	15,176	31,613
Website Costs	6,724	1,485
Other information Costs	13,531	12,238
Nurse Service - Travel & Meeting Costs	7,217	3,010
Nurse Service - Motor Car Expenses	20,683	18,306
Nurse Service - Car Lease rentals	36,399	36,575
Nurse Service - Mobile Phone Costs	4,754	3,453
Nurse Service - Other Costs	1,562	2,537
Service Support - Travel & Meeting Costs	355	110
Service Support - Other Costs	-	861
Comm Engagement General	245	-
Global Day Event	3,982	-
Staff Recruitment costs	7,846	13,990
Training	1,015	2,725
Health and Safety	43	955
Staff Support Costs	4,507	6,594
Travel & Subsistence	6,053	538
Revenue approved staff development costs	15,763	7,013
Conference - Symposium	6,851	752
Post & Courier	946	4,460
Stationery	3,676	2,670
Sundry Office Expenses	7,610	13,019
Printing	824	2,833
AGM Expenses	5,481	99
Office Equipment	1,797	-
Computer/Software Running Costs	9,141	3,071
Telephone Charges	4,134	8,059
Rent & Service Charge	99,222	93,583
Electricity	9,843	3,837
Bank Charges	5,295	4,459
Credit Card machine rentals	474	498
Charges for donation website	36,784	36,527
Audit/Accountancy Fees	11,382	11,163
IT Support & Maintenance	13,201	3,646
Other Professional Fees	8,979	9,050
Professional Fees Redundancies	-	2,175
Legal Fees	1,476	554
Insurance	7,296	5,744
Subscriptions	8,101	7,079
Miscellaneous Expenditure	114	-
Depreciation On Fixed Assets	7,034	5,589
Profit/Loss on Disposal of Fixed Assets	417	-
	<hr/> 396,200	360,870
Total Costs	<hr/> 2,833,408	2,380,121

**Irish Motor Neurone Disease Association**

Unit 3, Ground Floor
Marshalsea Court
22/23 Merchant's Quay
Dublin 8

Phone: 01 670 5942

Information & Support Line: 1800 403 403

Client Services & Support Email: services@imnda.ie

General Enquires Email: info@imnda.ie

Charity Registration Number: 20021009

CHY: 8510

Chief Executive Officer: Lillian McGovern

Voluntary Board of Directors:

Jonathan Healy, Chairperson
Alison Gray, Treasurer
Katie Hallissey, Secretary
Gillian Lynch, Board Member
Bernie Conolly, Board Member
Norman Hughes, Board Member
Lisa Doherty, Board Member
Joe Ritchie, Board Member
Prof Peter Bede, Medical Patron