Niemann-Pick
DISEASE GROUP (UK)
Registered charity No. 1144406

Niemann-Pick Disease Group (UK)

Annual Report 2012 -2013

www.niemann-pick.org.uk

Trustees Report

David Roberts, Chairman, NPDG (UK)

Throughout this year's Annual Report you will see how the Group has made a positive difference to the families affected by Niemann-Pick disease.

There are many stories and examples of how the tremendous work carried out by our staff and clinical nurse specialist is bringing about benefits to children and adults affected by Niemann-Pick diseases, their families and carers. I would like to thank them all for delivering such high quality services.

As well as providing care and support to families, we have also been working, in collaboration with other Patient and Umbrella Groups to influence policy on NHS reform, the changing role of the National Institute for Health and Care Excellence (NICE) and the UK plan for rare diseases. We continue to engage with these groups and our collective achievements have been reported in newsletters and bulletins.

We also have strong networks within the research community and have been closely following the phase 1 NPC Cyclodextrin Clinical Trial at the National Institutes of Health in Bethesda, U.S.A. This trial brings much hope for the future and we will be discussing with health care professionals how the NPDG (UK) could support the possibility of a clinical trial here in the UK. In addition, we have seen Phase 1b of the Genzyme led ASMD NP-B trial recently commence in Manchester, providing more exciting and encouraging news for the Niemann-Pick community.

We continue to review our key performance indicators and strategic objectives and are committed to involving our staff, families and supporters in shaping our future. However, whilst looking ahead, we are also focussed on the present day needs of the families and carers affected by Niemann-Pick diseases and we will continue to provide our much-needed care, advice and support services.

I would like to thank the Board of Trustees, staff members and volunteers for helping to manage and bring about the changes of the last 12 months. Their collective experience, knowledge and skill with which they represent us in the many arenas that affect our group of diseases is much needed and appreciated. Special thanks go to Richard Brooks, who recently stepped down as Trustee and Treasurer after many years of loyal support, dedication and generosity.

Our work both in the past and in the future could not be accomplished without the generosity of the many supporters of the NPDG (UK) – including families, friends and grant giving organisations. The Charity relies solely upon fundraising, donations and grants for our existence and I would like to acknowledge the huge efforts of everyone whose contribution enables us to make a difference. How we spent the funds raised is detailed in the financial section on page 16.

It is a privilege to be part of the NPDG (UK) and with your continuing support, I look forward to making a greater difference to families in the year ahead and to enabling further research into these devastating diseases.

David Roberts

David Roberts
Chairman, NPDG (UK)

About the Niemann-Pick Disease Group (UK)

Structure and Governance

The Niemann-Pick Disease Group (UK) is a charitable organisation offering support and information to families affected by Niemann-Pick diseases and to associated professionals.

The Charity was formed by a small group of parents in 1991 and in 1997 was granted charitable status as an independent charity, registered with the Charity Commission for England and Wales as an unincorporated association, registered charity number 1061881.

In January 2012, whilst remaining a registered charity, the NPDG (UK) changed its unincorporated charitable status to that of a charitable company limited by guarantee registered in England and Wales, company number 07775835, registered charity number 1144406. The name, assets, liabilities and activities of the Group were transferred into this charitable company on 1 January 2012.

The NPDG (UK) conforms to the requirements of both Companies House and the Charity Commission for England and Wales and has adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued in March 2005. The NPDG (UK) is governed by its Memorandum and Articles of Association, and is managed by a Board of Trustees, who for the purposes of company law, are also the Directors of the Group.

"The Board of Trustees, all of whom are volunteers, primarily consist of people who have family members or friends directly affected by this group of diseases."

NPDG (UK) Trustees meet at least four times a year and are responsible for all of the activities the Charity undertakes, with operational assistance from a number of Sub-Committees.

Our staff team are central to achieving our objectives; providing support, information and advocacy services and raising much needed awareness of Niemann-Pick diseases plus the social and economic challenges faced by those affected. Since 1999, the Group has funded the salary of a full time Clinical Nurse Specialist, providing expert care and practical advice, plus home visits whenever necessary. Genetic counselling and advocacy services are also provided:

- Following the retirement of Clinical Nurse Specialist Jacqueline Imrie after 12 years of dedicated service, her successor Laura Bell, took up post in September 2012.
- Elizabeth Davenport, NPDG (UK) Families Officer, provides an individual non-clinical advice and information service for affected individuals and their families.
- The Group's Executive Director, Toni Mathieson, and Information Officer, Sue Lowe, manage the NPDG (UK) Central Office, operating a 24 hour helpline and ensuring the smooth running of the Group's day to day activities.

Most importantly, the Group would not exist without the support of our members, friends and families; their efforts are vital in assisting the achievement of our aims and objectives.

About the Niemann-Pick Disease Group (UK)
Risk Management

The Board of Directors have considered and reviewed the possible risks to which the Group may be exposed, and have established the following risk management process:

- The development and implementation of a risk register
- Quarterly risk reviews
- Procedures to identify and mitigate risk

The major risks identified this financial year include:

- Succession planning for Trustees and the development of skills
- Economic and social pressures adversely affecting incoming resources
- The effect of NHS and Welfare Reforms on services for those affected by Niemann-Pick diseases

Actions are being developed to address these risks and will be communicated when formalised through newsletters, bulletins and letters as appropriate.

About the Niemann-Pick Disease Group (UK)
Aims and Objectives

The main aims and objectives of the NPDG (UK) are; to make a positive difference to the lives of those affected by Niemann-Pick diseases (NPD), relieve sickness and any distress which may arise there from, and to advance the education and awareness of families, professionals and the general public in all matters concerning the disease.

The NPDG (UK) aims to meet these objectives through:

- The provision of a support and advice service for families and individuals and associated health and social care professionals,
- The collection, collation and dissemination of relevant information,
- The provision of support for national clinical centres of expertise for Niemann-Pick diseases,
- The promotion of relevant research,
- The promotion of national and international collaboration.

To achieve our objectives, we rely on funding from voluntary donations, corporate donors, charitable trusts and statutory bodies, plus the fundraising support of our members, friends and families. Our goal is to ensure the continuation, and the successful delivery, of the services we provide, whilst seeking sustainable expansion.

To ensure our objectives support the needs and wishes of those we support, we undertake regular consultation with our members, supporters and stakeholders.

What is Niemann-Pick Disease?

Niemann-Pick diseases are a group of rare, inherited, metabolic conditions that can affect children and adults. These conditions are caused by specific genetic mutations and are pan-ethnic.

There are two commonly recognised forms of the disease: Acid Sphingomyelinase Deficiency (ASMD) Niemann-Pick Disease Type A and Type B represent opposite ends of a spectrum of the same disease, characterised by a deficiency of an enzyme which causes a build up of toxic materials in the body's cells.

Niemann-Pick Type C is not caused by an enzyme deficiency, but the end result is the same; an accumulation of materials (lipids and other fatty acids) in the body's cells.

Acid Sphingomyelinase Deficiency (ASMD) Niemann-Pick Disease

ASMD Niemann-Pick Types A & B, rather than being two separate 'types' of the disease, actually represent the opposite ends of a spectrum of the same disease, both caused by a deficiency of the enzyme Acid Sphingomyelinase. Many variations exist within this spectrum, in terms of clinical symptoms and rate of progression.

ASMD Niemann-Pick Disease Type A (NP-A)

ASMD NP-A is a rapidly progressive neurological disease that usually reveals itself within the first few months of a baby's life. Symptoms may include early feeding difficulties, failure to thrive and an abnormally large abdomen. Life expectancy rarely exceeds five years of age.

"We had a letter from the NPDG (UK) Niemann-Pick Nurse. The letter said "if there is anything that I can do"!!!! No more had to be said. I got on the phone and explained what we needed. Within the week our lives were easier…"

ASMD Niemann-Pick Disease Type B (NP-B)

In ASMD NP-B there is generally little if any neurological involvement. Symptoms can include an enlarged liver and spleen, delayed puberty, susceptibility to respiratory infections and increased stress on the heart. Most patients will survive into their teens and adulthood.

"How do I cope with living with ASMD NP-B? I live my life to the max, of course it scares me but life is a lottery….I am lucky that I have great people around me who support and encourage me"

Niemann-Pick Disease Type C (NP-C)

The presentation of NP-C is very variable and the onset of symptoms may occur at any time from early infancy to adulthood. Life expectancy varies considerably and there are a variety of symptoms. These may include an enlarged spleen and liver and, in newborn babies, there may be prolonged jaundice.

The disease is neurologically degenerative leading to progressive loss of motor skills and difficulty with walking. Speech can become slurred and swallowing problems may develop. Patients may experience sudden loss of muscle tone, which can lead to falls, also epileptic seizures that are generally difficult to control.

A symptom that is particularly suggestive of NP-C is difficulty with upward and downward eye movement. In those young adults, where onset is later, psychological problems and dementia can be major symptoms.

Is there a Cure?

At present, there is no cure for the Niemann-Pick diseases, although there is considerable research activity taking place around the world. Currently, those affected may benefit from supportive treatments - individual medication to treat the symptoms of the disease.

Research and Treatment

Over the years the NPDG(UK) has built a strong working knowledge in the field of NP research. By developing and sustaining robust relationships with key figures and organisations across the world, the Group is kept up to date with research that is taking place, its status and where it is happening.

Our extensive clinical experience, built up through the existence of a clinical centre and a clinical nurse specialist, assists us in encouraging research and trials here in the UK. During the year, the NPDG (UK) has played a key role in supporting and facilitating research projects at both Cardiff University and the University of Oxford.

Recent advances in characterisation and understanding of the disease have led to a number of possible therapeutic targets being identified. Enzyme replacement therapy is currently being investigated for ASMD NP-B and studies are looking at potential therapies for NP-C.

Public Benefit

The Trustees confirm that they have complied with the duty in section 4 of the Charities Act 2006 and when planning our activities for the year, the NPDG (UK) Trustees carefully consider the Charity Commission's guidelines on Public Benefit. Through our work, we aim to ensure that each individual affected by, or connected to, this disease, is able to access the best possible care, support and information appropriate to their needs. In working towards our charitable aims, the Group undertakes a wide range of activities in the three key areas of **Care and Support, Information and Research**:

Unique Care and Support Services

The NPDG (UK) provides a unique care and support service to families affected by the Niemann-Pick diseases. The service has been developed over a number of years and is closely monitored to ensure that each activity is of value and benefit to the community we support.
This year we have;

- Provided support and information to families and associated professionals in the form of a 24-hour help line, a comprehensive website, educational literature, regular newsletters and bulletins.

- Continued to fund the post of a dedicated Clinical Nurse Specialist for Niemann-Pick Diseases, with support from family fund raising, BBC Children in Need and The Big Lottery Fund.

"We contacted the NPDG (UK) Clinical Nurse Specialist (CNS) when our child was experiencing difficulties with naso-gastric feeding. We immediately received advice on positioning and suggestions for the use of aids and adaptations to her wheelchair that could provide further help. To further assist, the CNS referred us to our local Speech and Language Therapy Team."

- Offered UK wide networking and mutual support opportunities for families through the organisation of an Annual Family Conference, Clinic Days, a website e-forum, social networking sites and the production of a Family Directory.

- Continued to fund the post of NPDG (UK) Families Officer, offering an individual advocacy service, including home visits and assistance at clinic appointments and providing non-clinical advice, information and support.

- Involved volunteers in working with NP families through the Children and Young Persons' Activity Programme at our Annual Family Conference; ensuring they receive the training and support they need to fulfil this valuable role.

Interactive Family Care and Support Project

In 2010, the NPDG (UK) launched the 'Interactive Family Care and Support Project' to tackle isolation and despair faced by families coping with Niemann-Pick type disease.

The overall aim of the project, now in its third year, is to overcome isolation and improve the quality of life of families coping with Niemann-Pick diseases, through the use of interactive technology such as video cameras and media links, to improve access to advice and information from the NPDG (UK) Clinical Nurse Specialist (CNS), and their own health care team. In particular, the project helps those families who may feel isolated, or who are struggling with the challenges associated with Niemann-Pick disease.

The project enables families who would benefit from additional contact with the NPDG (UK) Clinical Nurse Specialist, or their own Healthcare team, to access advice and support in a timely and effective way – via the use of technology. This service does not take away the need for regular appointments or face to face meetings; it simply provides supplementary help and has increased the capacity of our own organisation to support more families.

The provision of interactive technology has enhanced the services we provide by assisting families facing disease progression and changing symptoms, enabling them to access immediate advice or to provide evidence of symptoms or behaviour that occur outside of clinic appointments. The interactive media technologies have also been used to strengthen links between families affected by the disease, who are often geographically isolated and for whom travel can be extremely difficult.

The Project has so far exceeded expectations and the services provided have become an integral part of the NPDG (UK) support programme.

At our 2012 Annual Family Conference, 140 stakeholders and family members were consulted regarding their opinions and ideas regarding NPDG (UK) services past, present and future. The addition of the Interactive Family Care and Support Project received many positive comments, including:

"Excellent methods of contact – everyone at the NPDG (UK) very open and accessible"

"Most helpful service –provides excellent support – always someone to turn to".

Our Services

Clinical Nurse Specialist and Families Officer

We provide a unique care and support service to families affected by the Niemann-Pick diseases; our aim is to ensure that each family or individual receives the level of support they require to meet their needs.

Our Clinical Nurse Specialist provides expert support, advice and information regarding all aspects of the Niemann-Pick diseases:

- An individualised advice service via phone/email/internet
- Clinical care
- Genetic counselling
- Bereavement Counselling
- Help in navigating the NHS
- Home visits
- Teaching sessions for Schools

Our Families Officer provides non-clinical advice, information and support on an individual basis:,

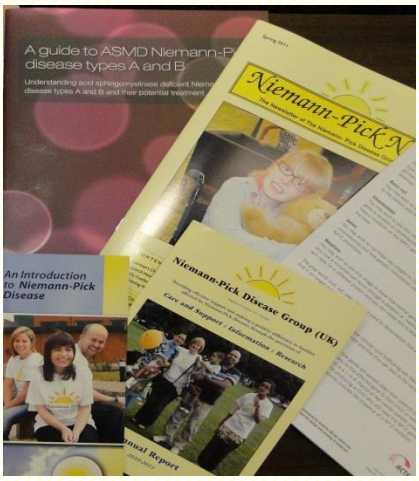
- Home visits and assistance at clinic appointments.
- Advice, reassurance or just a friendly voice at the end of the phone.
- Benefits advice
- Special Educational Needs and help with Statements
- Housing, aids and adaptations

Our Services

Information and Awareness

The NPDG (UK) recognises the need to provide current, relevant, information and news regarding all aspects of the Niemann-Pick diseases in a timely manner. We produce a wide range of informative materials and educational resources to assist families and professionals in dealing with all aspects of the Niemann-Pick diseases. These are regularly updated to reflect the changing needs of those we support.

During the year we have:



- Distributed our bi-annual Newsletter "Niemann-Pick News" plus e-bulletins to our members and supporters free of charge
- Continued to develop and distribute educational information on Niemann-Pick diseases to support families and professionals
- Encouraged close working relationships with other Niemann-Pick and associated disease groups to share information, stimulate interest in, and further the knowledge and understanding of this group of diseases

- Organised an Annual Family Conference to encourage the sharing of knowledge and experience between families and professionals
- Organised a Workshop specifically for health professionals and providing the opportunity to share the latest information regarding clinical care and scientific advances
- Given talks and presentations at conferences and fundraising events across the UK, including educational talks to schools, hospitals and hospices

We have an on-line presence via our website, which is currently being updated, and through social media sites such as Facebook and Twitter.

International Niemann-Pick Disease Alliance

The International Niemann-Pick Disease Alliance (INPDA) was formed in 2009 with a view to providing a forum where, through the exchange of information, experience and knowledge, progress could be accelerated.

The INPDA brings together non-profit Niemann-Pick support organisations from around the world. Members include: Argentina, Australia, Brazil, Canada, France, Germany, Italy, the Netherlands, Spain, USA and the United Kingdom.

The Alliance provides a network that enhances the transfer of information, maximizes the use of resources and demonstrates that collectively, Niemann-Pick diseases are not as rare as was once thought. By sharing in this way, we will facilitate progress and avoid duplication of effort.
Further information can be found at www.inpda.org

LSD Patient Organisation Collaboration

Lysosomal storage disorders (LSDs) are a group of approximately 40 rare inherited metabolic disorders that result from defects in lysosomal function, including the Niemann-Pick diseases.

Lysosomal storage disorders (LSDs) result when a specific organelle in the body's cells – the lysosome – malfunctions. All LSDs share a common pathogenesis: a genetic defect in a specific lysosomal enzyme, receptor target, activator protein, membrane protein, or transporter, leading to accumulation of substrates in cell lysosomes.

The LSD Patient Organisation Collaborative consists of representatives from the Association of Glycogen Storage Diseases, Batten Disease Family Association, the Gauchers Association, the Society for Mucopolysaccharide Diseases, Save Babies Though Screening Foundation - representing Krabbe Disease, and the Niemann-Pick Disease Group (UK).

As part of this collaboration, the Niemann-Pick Disease Group (UK) has undertaken to jointly promote and share understanding of these diseases, to advance standards of care and to enhance the well-being of those affected. In 2012, The LSD Collaborative undertook a lobbying campaign to highlight the potential impact of NHS and welfare reform. Having achieved recognition, the LSD Collaborative now has a strong voice with which to advocate for all patients affected by this group of disorders.

Annual Family Conference 2012

The 19th NPDG (UK) Annual Family Conference was held 21st – 23rd September 2012, at the Robinson Executive Centre, Wyboston Lakes, Bedfordshire.

2012 was a special year for the NPDG (UK); we celebrated 21 years of providing care, support and information to families affected by Niemann-Pick diseases.

The Conference theme; ***"People, Purpose and Passion for 21 Years"*** recognised the achievement of those whose dedication, drive and determination has made such a difference to so many since the Group began in 1991.

The event started on Friday 21st September with the 3rd Interactive Workshop on Niemann-Pick Diseases, exclusively for professionals working in the field of Niemann-Pick diseases.

This year delegates from the UK, USA, France, Spain, Germany, Chile, Italy and Argentina and were given the opportunity to share current information regarding all aspects of Niemann-Pick diseases, including clinical management, research and potential therapies, and to debate the future of treatment and care for those affected.

The ***19th NPDG (UK) Annual Family Conference*** began on Friday evening; this year we welcomed ten new families to the Conference and were delighted to meet families from Canada, Norway and France. Families once again had the opportunity to hear the latest developments regarding research, therapies and related care issues from experts in the field of Niemann-Pick diseases. Our Family Voices spoke from the heart about their family's experience with NPD, each providing their own unique and touching views, which were recognised and appreciated by all.

Children and Young Person's Activity Programme

Alison Hitchins and her dedicated team of volunteers once again entertained our children and young adults, organising a fun-packed weekend of activities, including a trip to the cinema, bowling and a range of 'olympic games'.

Many thanks go to our volunteers and our Conference Sponsors, Actelion Pharmaceuticals UK, Actelion Global, Genzyme, A Sanofi Company and Dr Hetti Davies, without whom this event would not be possible.

ACTELION

genzyme

Facilitating progress towards therapeutic interventions for all of these diseases is central to everything we do in the NPDG (UK) and has been for the past 21 years. This year we have:

- Maintained links with clinicians, scientists and pharmaceutical companies in the development of possible therapies for Niemann-Pick diseases, through support for clinical trials for patients with ASMD Niemann-Pick Type B and Niemann-Pick Type C, both in the UK and in the USA.

- Actively supported and, where appropriate, funded scientific research into the Niemann-Pick diseases.

- Nurtured the interest of young Niemann-Pick researchers through 'The Peter Carlton Jones Memorial Award', granted in response to the submission of an original contribution to the scientific or public understanding of the Niemann-Pick diseases and/or their treatment or cure.

- Monitored scientific advances and effectively communicated news in a number of different formats – such as through our website, newsletter, social media and bulletins.

Influencing Research

The NPDG (UK) Board of Trustees is made up of people who have family members or friends directly affected by this group of diseases. We understand the urgency to find effective therapies and the fact that progress never seems to be fast enough.

We actively encourage Niemann-Pick disease research through the relationships we foster and the networks we contribute to. By sharing knowledge and expertise and by working together, we believe progress will be even faster.

The NPDG (UK) aims to maximise the benefits of funding, by working in partnership with like-minded organisations in pursuit of a better understanding and a cure for Niemann-Pick disease. This year, we have been able to grant fund projects at the ***University of Oxford*** and at ***Cardiff University,*** and to support two PHD students in attending the prestigious ***Gordon Research Conference on Lysosomal Diseases.***

The Annual Peter Carlton Jones Memorial Award was this year presented to Danielle Taylor te-Vruchte, a Research Assistant in the Department of Pharmacology at the University of Oxford. The Award is granted in response to the submission of a research project which provides an original contribution to the scientific or public understanding of the Niemann-Pick diseases and/or their treatment or cure. Danielle's winning project was based around the application of cell based assays to the therapeutic monitoring of the glycosphingolipidoses.

With potential therapies being trialled and research projects actively pursued within the field of Niemann-Pick diseases, there is a need for the NPDG (UK) to facilitate and support clinical and scientific research as much as we can, and to report the findings to our members. Through our activities this year, and our support for clinical centres of excellence here in the UK, we are encouraging the development and progress of such clinical trials and working to implement effective support systems for families wishing to participate.

Our Objectives for the Coming Year

Care and Support

- To continue the provision of our Care and Support Service.
- To provide the services of a Families Officer delivering non clinical advice and support.
- To support the continuation of effective, expert services for families affected by Niemann-Pick diseases within the NHS.
- To maintain funding to support the role of Clinical Nurse Specialist for Niemann-Pick Diseases.

Providing Information

- To continue providing up to date and accurate information on all aspects of Niemann-Pick Disease; by means of the NPDG (UK) Central Office and Clinical Nurse Specialist, educational resources, newsletters/e-bulletins, the website and telephone help line.
- To develop and improve our website, provide current content, direct news feeds and a discussion forum.
- To involve families in the review of services and development of resources.

Research

- To promote Niemann-Pick disease research through the relationships we foster and the networks we attend.
- To support and encourage Niemann-Pick research by making grants available to laboratories working on this group of diseases.
- To position ourselves in support of clinical trials and to help families prepare for trials when the clinical conditions and funding becomes available.

Enabling the Work of the Group

Grant Funding

We continue to seek ways to sustain and improve our current services and allow for future growth. In 2012/2013 we have been thankful for the support of the following grant giving organisations:

LOTTERY FUNDED

The Big Lottery Reaching Communities Programme continued to support our 'Family Care and Interactive Support Service.' This innovative project uses interactive media technologies to provide support to families affected by the Niemann-Pick diseases. Now in its final year, the project has exceeded expectations and has become embedded within our Care and Support service.

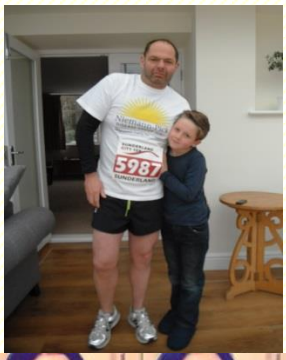
The Group is once again grateful for the continuing support of Children in Need who provide a grant to meet one third of the cost of salary for our Clinical Nurse Specialist.

BBC Children in Need

Fundraising and the NPDG (UK)

The Efforts of our Families, Friends and Supporters

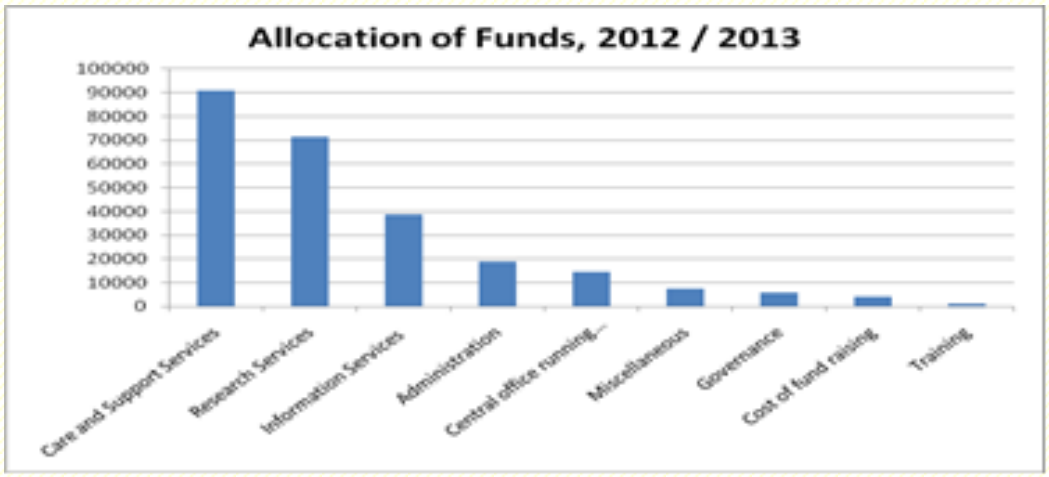
We are extremely grateful to all those who support of our work. The Group would not be able to meet the needs and expectations of families affected by this group of diseases without donations and funds raised by the activities of our members, families and friends.



Except for those donations that were restricted for use, all general donations and money raised by families during the financial year, 2012/2013, was allocated to our Care and Support Services and Research Services.

We recognize the tremendous effort that goes into organising fund raising events and, at a time of increasing economic uncertainty, it is important we develop funding streams that are capable of sustaining the future of the Group.

The following chart shows how the Group uses funds raised to meet its aims and objectives and demonstrates the need, and the importance, of your support and that of our grant funders, as being vital to the continued funding of our support services



Financial Review

The NPDG (UK) Board of Trustees approved a financial forecast and budget for 2012/2013 which showed a reduction in assets in order to fund the core services of care and support, information and research. This is shown in the Financial Accounts as a reduction in funds of £34,405. This was felt necessary to ensure that research was adequately funded alongside care, support and information.

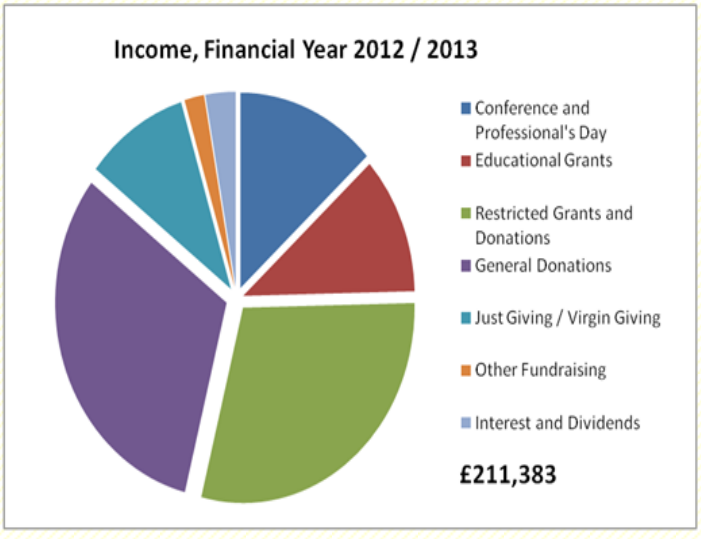
In an uncertain economic climate, the Endowment Fund continued to out-perform the market and increased in value from £210,435 to £217,747. In addition we benefited from an investment income of £5,953. The endowment fund is expendable, but is restricted for use to finance the family care and support service as and when required.

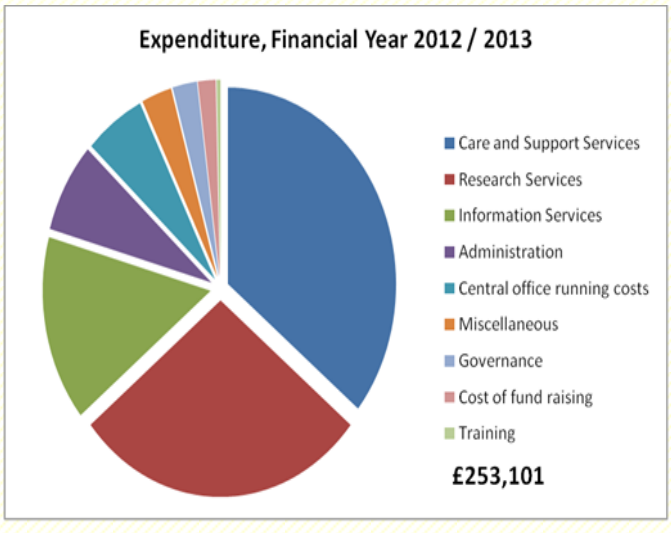
The total income for 2012/2013 was £211,384 of which £90,939 was raised by donations and fundraising activities through the generosity of families, friends and supporters. Without this support we would not have been able to provide the core services that so many families have come to expect. In addition, £60,453 was raised through grant giving organisations and the income from all other sources was £59,992. This included £27,899 from pharmaceutical companies, which was allocated to our Annual Family Conference and Interactive Workshop, plus other educational grants totalling £24,144.

Funding our core services from net assets means that our bank balance has been reduced from £110,519 to £68,802. This places extreme importance on finding additional funding streams and managing our priorities, expenses and cash flow.

Additional pressure during the financial year 2013/14 will be created by an increasing need to fund research programmes and by the rising demand for our Care and Support services; as more patients are diagnosed and families require additional help to navigate the changes within the NHS and welfare systems. However, with the continuing support of our families, friends and supporters we can look forward to another year of providing care and support, information and research services.

The following charts show the total incoming resources for 2012/2013 reproduced from the Report and Financial Statements for the year ending 30th April 2013. The complete financial statement can be viewed at www.niemann-pick.org.uk





Reference & Administration

Charity Trustees / Board of Directors

David Roberts (**Chairman)**
Richard Brooks **(Treasurer)**
Bill Owen
Helen Carter
Prof. Frances Platt (Co-opted)
Jim Green
Janice Brooks
Richard Rogerson
William Evans

Registered Charity Number: 1144406
Company Limited by Guarantee Registered in England and Wales No: 07775835
Secretary: Toni Mathieson

Medical Advisor
Dr Simon Jones
Consultant in Paediatric Inherited Metabolic Disease
Genetic Medicine, St Mary's Hospital
Manchester Academic Health Sciences Centre Central Manchester University Hospitals NHS Foundation Trust

NPDG (UK) Registered Address:
Suite 2, Vermont House
Concord, Washington,
Tyne and Wear
NE37 2SQ

Telephone Helpline: 0191 415 0693
E-mail: niemann-pick@zetnet.co.uk
Website: www.niemannpick.org.uk

Bankers
HSBC, Grays Branch
53, High Street, Grays, Essex
RM17 6NH

Auditors
James Anderson & Co,
Chartered Accountants,
Pentland Estate, Straiton,
Edinburgh
EH20 9QH

Thank you!

We are very grateful to everyone who has supported our work this year.

We have received generous funds from families, siblings and friends, community groups, places of work, clubs and school children.

Fundraising events have been many and varied from walking, running, sky diving and mountain climbing to grand balls, concerts, golf days and fire walking.

Your continuing support will ensure that we continue to provide our much needed services of care and support today whilst enabling research for the future.

Patrons
The Rt. Hon. The Earl Cairns, CVO, CBE; The Rt. Reverend Dominic Walker OGS, Bishop of Monmouth; Dora Bryan OBE, MA; The Rt. Hon. The Lord Bassam of Brighton; Professor Martin N Rossor, MA, MD, FRCP; Guy Johnston; Nicholas Mathias ARAM; Denise Nolan; Keith Andrews; Marie T. Vanier M.D. PH.D.