



Supporting those affected
by Niemann-Pick

Our
Care
& Support
Services

Introducing NPUK...

At NPUK, we are dedicated to making a positive difference to the lives of those affected by Niemann-Pick diseases (NPD). We offer emotional and practical support and information to individuals, their families, and to the professionals involved in their care, from diagnosis and beyond.

This booklet aims to provide you with an overview of our key services and to introduce you to our expert team, who offer a unique care and support service for those affected by Niemann-Pick disease and their families.

Our flexible and individualised support and advocacy service aims to ensure that each individual is able to access the level of support they require to meet their needs. Our team can help you to access beneficial services and equipment, and can provide helpful information, tools and resources that encourage understanding of Niemann-Pick disease and how it may affect your family.

Working closely with national and local health and social care providers ensures that our community is informed and has access to optimum care, treatment and services that can assist daily life and increase opportunities for independence and social interaction.

You can learn more about Niemann-Pick UK and the work we do on our website at: www.npuk.org

Annual Family Conference & Regional Activities

Our Annual Family Conference provides an opportunity to hear the latest developments regarding therapies and clinical trials for ASMD Niemann-Pick disease types A and B and Niemann-Pick type C, plus related care issues, breakout sessions and workshops.

"...support from the NPUK team and attending the Annual Conference made an incredible difference, without these things we would have felt very isolated and not had an understanding of the disease or any research and trials that are happening..."

As well as hearing the latest research and clinical updates, this weekend is about sharing information, meeting new people and making new friends. The informal atmosphere enables discussion and questions with the speakers both during their presentation sessions and through lunch, coffee and social time.

Thanks to our team of dedicated volunteers, we are able to provide a full range of activities for children and young adults, running in parallel with the main conference programme.



Clinical Advice & Support:

Meet Laura Bell, Clinical Nurse Specialist

Laura has held the post of NPUK Clinical Nurse Specialist since 2012 and has worked in the field of metabolic disease since 2008. Laura says:

"As Clinical Nurse Specialist for Niemann-Pick diseases, I am always available to offer clinical advice and support to you and your family regarding any aspect of Niemann-Pick disease."

Laura is dedicated to supporting families affected by Niemann-Pick disease, she understands the complexities and difficulties that families face on a daily basis. Laura can support you in navigating clinical care and provide practical advice and emotional support. Some of the other ways she supports families, alongside our team members, include:

- Home visits whenever necessary
- Directing and helping families to access their local healthcare services
- Liaising with health and social care teams, which may include your Occupational Therapist, Speech and Language Therapist or Social Worker
- Supporting families to understand the choices of care that may be available
- Working with schools and teaching staff to provide information and support on Niemann-Pick disease to support children in attending and achieving at school
- Accompanying individuals and families to clinic appointments or meetings
- Attending clinic days and supporting throughout appointments

"Without Laura I would not have had the help when I needed it. I would not have been able to explain my child's symptoms clearly and to get the help she needed."

"We contacted the NPUK Clinical Nurse Specialist with a question regarding our child's speech and head control and immediately received a response! Advice was given on positioning and the use of aids and adaptations, a Speech and Language Therapist was consulted and strategies developed to assist us. All of this from one contact!"

Based at Salford Royal Hospital in Manchester, Laura is a source of comfort and a great support to patients and their families, enabling them to better understand their condition and to make informed decisions about their treatment and care.

Laura brings compassion and dedication to her role, which is reflected in the relationship she has with the Niemann-Pick community. Laura says:

"To be able to support families with their NP-C journey is something that I and my colleagues at NPUK are passionate about. I feel honoured that families have agreed to share their journey with us."

You can contact Laura by telephone or email on: laura.bell@srft.nhs.uk or laura@npuk.org - or phone on: 0161 206 0228 / Mobile: 07791 499 555



Non-Clinical Advice & Support

Meet Elizabeth Davenport, Senior Families Advocate

Elizabeth has held the position of Senior Families Advocate since 2011, she is a qualified social worker with a vast knowledge of Niemann-Pick disease and the challenges faced by families living with the condition. Elizabeth is dedicated to supporting those affected, their families, carers, friends, education providers, employers and relatives. She offers non-clinical advice, information, and support to suit each and every person's individual needs. Working alongside other members of our team, Elizabeth aims to reduce feelings of isolation and despair, by visiting families at home, and by being available at the end of a phone or via email whenever needed.

Elizabeth says:

"It's always a pleasure to work with families and to achieve a positive outcome. For me this highlights that when we work as a team we can do great things. It may take time, with many emails and meetings and it can be stressful but when we finally get what the family needs it is all worthwhile."

"Having Elizabeth to contact people for us is a great help so we don't have to tell our story to every person over and over again. It can be stressful at times and she has even gone to meetings with us"

Some of the ways Elizabeth supports patients and families, alongside our care and support team, include:

- Home visits, whenever necessary
- Helping families to access local services and social activities
- Providing advice, information and support regarding welfare and benefits, including applications, legislation, appeals for the Personal Independence Payment (PIP); Employment Support Allowance (ESA); housing benefits, plus many more
- Seeking individual funds, grants or wishes for families, as required
- Liaising with housing authorities and occupational therapists to ensure patients and families can access aids and adaptations that will assist their daily life
- Providing opportunities for affected families to socialise and to make contact with each other via Family Fun Days, telephone calls, or through social media
- Providing support and advice for young siblings and young adult carers
- Support for families who are in crisis and liaison with outside agencies, as required
- Liaising with schools, higher education facilities and employers to provide information about NPD and to implement strategies for support.

You can contact Elizabeth using the following details: Email: elizabeth@npuk.org
Tel: 01904 438589 / Mobile: 07896 197 576



Meet Steve...

Steve Neal, Project Families Officer

Steve joined us in early 2017 to support our Big Lottery funded project "Shaping Our Future Together" - he has brought a range of skills and experience plus personal insight into NPD which helps him in his work to support families:

Steve says:

"My family and I have been a part of the NPUK community for a number of years as my mother is affected by NP-C. We have all taken advantage of the support and services that NPUK offer.

Knowing someone is there to call and talk to when trying to manage the challenges of this condition makes a massive difference. This has given me a great passion to help other families, and in my role with NPUK I will be dedicated to offering care, support and guidance."

As part of his role, Steve will be developing links, relationships, support services and resources for our increasingly diverse community, as well as undertaking research that will help us to better understand and support those affected by Niemann-Pick disease..

You can contact Steve using the following details: Email: steve@npuk.org Tel: 0191 415 0693 / Mobile: 07787 818 885

"Very few people understand the heartache and the heartbreak of being diagnosed with a rare disease."

Meet our Central Office Team:

If you call our helpline you may also speak to a member of our Central Office Team



Toni Mathieson:
Chief Executive

I became involved with NPUK in 2003, when our daughter was diagnosed with NP-C. I am now involved in all aspects of the Charity's work.



Christine Jopling:
Finance Officer

I have witnessed firsthand the direct impact that our charity has had on people's lives; we always do as much as we possibly can!



Louise Metcalfe:
Project Team Leader

As Team Leader for the Big Lottery funded project 'Shaping our Future Together', I am working to enhance the support already provided by NPUK.



John Lee Taggart:
Communications Officer

I help NPUK harness the power of social media, online platforms, and other forms of communication to increase our reach.

Our Central Office is based in Washington Tyne and Wear, however our team provides a service which spans the whole of the UK, including home visits whenever necessary.

You can get in touch with us anytime if you have questions or queries regarding Niemann-Pick disease, or the services NPUK offers, by email at: info@npuk.org or by phone on: 0191 415 0693.



TEAM WORK



Our care and support team work hand in hand with the team at our central office to ensure that your family receive optimum care and support.

We provide an individualised service to patients and their families across the UK, which includes clinical and non-clinical advice, information and support in the areas of health, education, transition, employment and housing. We also work closely with each of the UK Specialist Centres and liaise with patients' local social services and health care teams to ensure voices are heard and needs are met.

Our works helps to ensure that the rights of patients are protected, that

they are able to access the care and and treatment that they need in order to live as fulfilling a life as possible.

Our team can visit you at home, school or work, attend clinic appointments or simply provide a friendly voice at the end of the phone.

NPUK Clinical Nurse Specialist Laura Bell says:

"Here are just a few examples of the joint working we undertake as part of our Niemann-Pick UK roles. We aim to achieve positive outcomes for families to ensure their wellbeing, health and safety through team work and the support we can offer to patients, families and local services."

- A 24-hour helpline (0191 415 0693)
- A strong and supportive social media community
- An Annual Family Conference which brings our community together and offers the opportunity to hear the latest research and clinical developments
- Supporting families to undertake education and healthcare plans and school reviews
- Supporting families with the transition from child to adult services
- Attending multi-disciplinary team meetings and reviews for children, young people and adults
- Liasing with schools and social services about the needs of the individuals and providing them with information about NPD
- Hosting training sessions at schools with teachers and school nurses to help them understand more about Niemann-Pick disease
- UK-wide networking and mutual support opportunities for families



"Following our daughter's diagnosis, I took it upon myself to search out more information and found the contact details for NPUK. They were amazing – they kindly provided me with the support I needed and referred me to their Clinical Nurse Specialist, who gave my husband and I a clearer picture of the disease and what to expect"

"We now liaise directly with NPUK Team members - all of whom have developed a bond with our daughter and understand her as a person. This is so important for us, as she is very nervous about hospital visits."

"The NPUK Team have made a huge difference to how we cope with this condition"

NPUK is a charitable organisation dedicated to making a positive difference to the lives of those affected by Niemann-Pick diseases. We raise much needed awareness, provide practical and emotional support, advice and information and facilitate research into potential therapies

npuk.org

Niemann-Pick UK (NPUK)
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Scotland (SCO45407)
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England and Wales
(07775835)



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