



Supporting those affected  
by Niemann-Pick

**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 practical and emotional support and information to patients, their families and friends, and to the professionals involved in their care, from diagnosis and beyond.

This booklet aims to provide you with an overview of our work and to introduce you to our expert team, who offer a unique care and support service for all those affected by Niemann-Pick diseases.

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 diseases and how they 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](http://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, the conference 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 social time.

In parallel with the main conference programme, we aim to provide a range of fun activities for children and young adults, supported by our dedicated team of trained volunteers.





# 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 NPD 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](mailto:laura.bell@srft.nhs.uk) or [laura@npuk.org](mailto:laura@npuk.org) -  
or phone on: 0161 206 0228 /  
Mobile: 07791 499 555**





# Non-Clinical Advice & Support

## Meet Louise Metcalfe, Families Officer

Louise joined NPUK in 2016 and holds the role of Families Officer. She has a deep understanding of the challenges faced by our community and an expert knowledge of the practical and financial support available across the UK.

Louise offers non-clinical advice, support and information to patients and families affected by Niemann-Pick disease plus their extended family members and friends. She provides a range of practical and emotional support services to enhance and improve daily life, from a friendly chat over the phone, to help with benefit applications, advice regarding practical aids and housing adaptations and support for children and young people accessing education.

Her UK-wide role means Louise can provide virtual support or visit you at home, at school, in your workplace, or accompany you to hospital or other appointments. She works closely with our Clinical Nurse Specialist, plus national and local health and statutory services, and is always ready to help, support or provide guidance.

*"...having Louise help me negotiate the complex world of education, care and benefits and everything else my child needs takes the weight off my shoulders and allows me to enjoy quality time with my family..."*

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

- Helping families access local services such as play schemes, home care and respite and group activities.
- Providing advice and support when applying for benefits such as DLA, PIP, ESA and Carers Allowance etc.
- 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.
- Working with families, schools and other local agencies to ensure children and young people get the support they need at school.
- Liaising with higher education providers and employers to give info on NPD and related care issues.

*You can contact Louise using the following details: Email: [louise@npuk.org](mailto:louise@npuk.org)  
Mobile: 07423 106 595*





# Meet Steve...

## Steve Neal, Counselling & Wellbeing Officer

Steve joined NPUK 2017, bringing a range of skills and experience plus personal insight into Niemann-Pick disease, 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 was affected by NPC. As a family, 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 and this has given me a great passion to help other families."

Steve can offer practical mental health and well-being support to individuals affected by Niemann-Pick disease and their families.

Support is confidential and can be provided in-person and / or via virtual platforms. Steve can assist with a range of issues, including personal, emotional and relationship issues. Working alongside the NPUK staff team, and collaboratively with local services, Steve is able to provide appropriate advice and signposting, or just to be there when you need a friendly chat.

*You can contact Steve using the following details: Email: [steve@npuk.org](mailto: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 NPC. I am now involved in all aspects of the Charity's work.



**Christine Jopling:**  
Finance & Admin Officer

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



**John Lee Taggart:**  
Communications & Campaigns Manager

I harness the power of social media, online platforms, and other forms of communication to connect and inform the NPUK community.

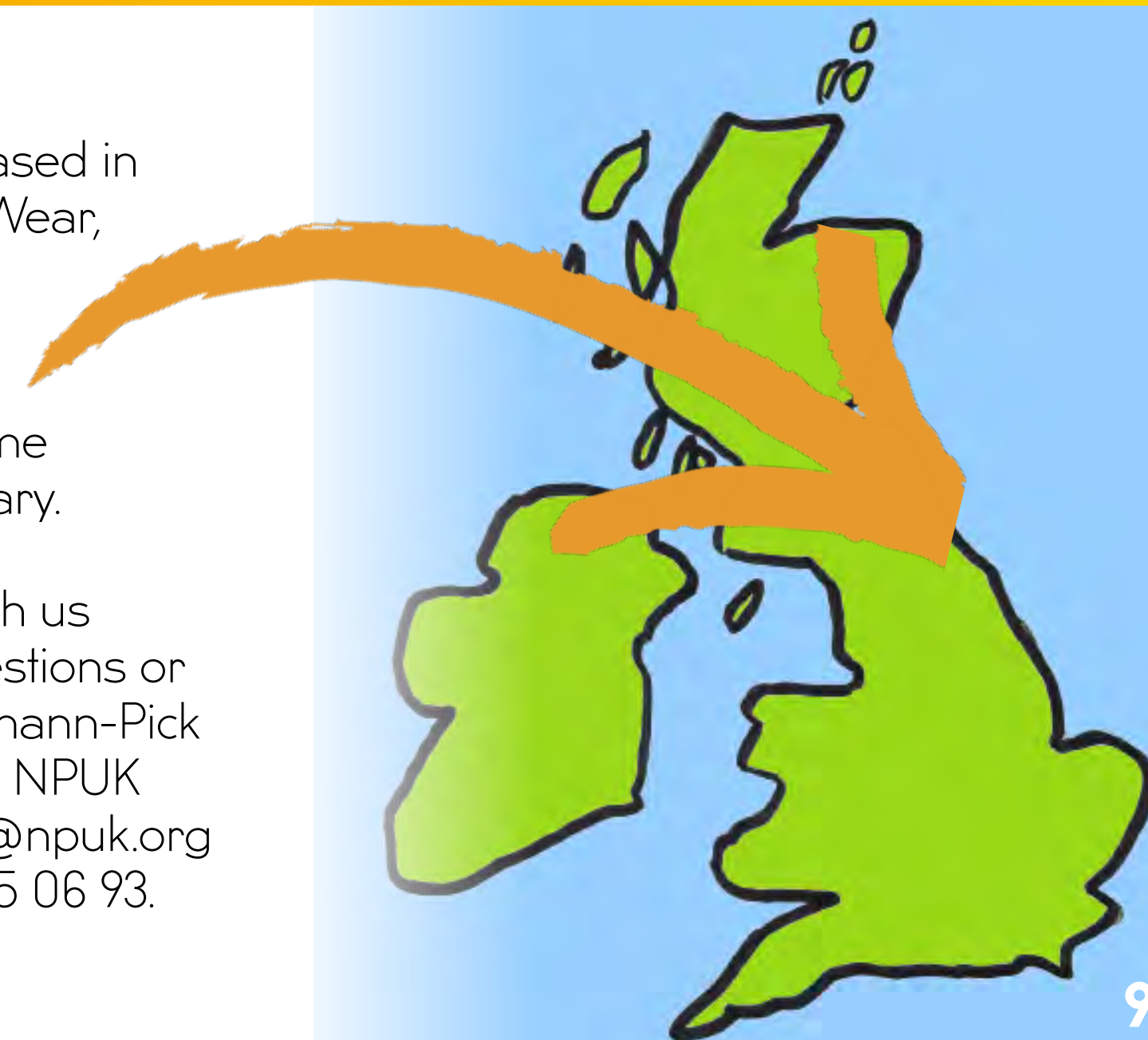


**Jenny Charman:**  
Fundraising Officer

My role involves supporting the vision and purpose of NPUK by aiding with the collection of essential funds.

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](mailto:info@npuk.org) or by phone on: 0191 415 06 93.







- A 24-hour helpline (0191 415 06 93)
- 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
- Liaising 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

**Our Care and Support team work hand in hand with the team at our central office to ensure that you 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 Clinical Centres and liaise with patients' local social services and health care teams to ensure voices are heard and needs are met.

Our work helps to ensure that the rights of patients are protected, and that they are able to access the care

and treatment 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 support via on-line platforms.

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."



"...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..."

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

"...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..."



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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Email: [info@npuk.org](mailto:info@npuk.org)  
Tel: 0191 415 0693

Registered Charity:  
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Scotland (SCO45407)  
Registered as a company  
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England and Wales  
(07775835)

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With grateful  
thanks to our  
grant providers:

