





 <p>NP-Argentina.org</p>	<p>Niemann Pick Argentina ARGENTINA Established 2005</p> <p>Supporting ASMD and NPC Estimated NPD Patients:</p> <ul style="list-style-type: none"> ASMD / approximately 10 NPC / approximately 30 	 <p>Marcelo Minotti mminotti@gmail.com npcargentina@gmail.com</p>
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Our mission is to have a positive impact on the lives of those affected by Niemann-Pick disease, providing support and information, disseminating the characteristics of the disease for a timely diagnosis and adequate treatment, and promoting their research towards a cure.







Our objective is to provide support to affected families, anticipating, and responding to the various needs that arise during the different stages of the disease.

 <p>npcd.org.au</p>	<p>Australian NPC Disease Foundation Inc. AUSTRALIA Established 2009</p> <p>Supporting NPC Estimated NPD Patients:</p> <ul style="list-style-type: none"> NPC / 28 	 <p>Mandy Whitechurch mandy@npcd.org.au</p> <hr/>  <p>Deanna Carpino deanna@npcd.org.au</p>
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Committed to supporting Australian patients of NPC and their families and to funding research for better treatments or a cure of NPC.

 <p>boks.be</p>	<p>BOKS (Belgische Organisatie voor kinderen en volwassenen met een stofwisselingsziekte) BELGIUM Established 1994</p> <p>Supporting ASMD and NPC Estimated NPD Patients:</p> <ul style="list-style-type: none"> ASMD / 4, possible more unknown NPC / Unknown 	 <p>Wim Porto-Carrero wimportocarrero@gmail.com</p>
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Promoting the interests of people affected by a metabolic disorder. This we aim to do in a broad sense: patient advocacy, informing patients, bringing patients together and supporting them after diagnosis.

 <p>facebook.com/ NiemannPickBrasil</p>	<p>Associação Niemann-Pick & Batten Brasil BRAZIL Established 2010</p> <p>Supporting ASMD and NPC Estimated NPD Patients:</p> <ul style="list-style-type: none"> • NPC /100 • ASMD /30 <p> </p>	 <p>Rejane Machado rejanemsmachado@gmail.com</p>
		 <p>Marie Helena Dorado hdourado10@gmail.com</p>
		 <p>Graham North Translator Assistance graham.david.north@gmail.com</p>

Our goal is to be a national reference institution of support for Niemann-Pick (type A, B and C) and Batten disease in all stages of accessible treatments and integrating families, professionals, laboratories, government and community.

 <p>facebook.com/npbrs</p>	<p>Niemann-Pick B R-S BRAZIL Established 2014</p> <p>Supporting ASMD Estimated NPD Patients:</p> <ul style="list-style-type: none"> • ASMD /30 <p> </p>	 <p>Claubia Viegas Bender claubia_bender@hotmail.co</p>
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Our goal is to transmit quality information through social media. We are focused on communication, on facilitating patient access to health systems, on clinical trials and guidance on how to try to access high-cost medication.

 <p>niemannpickcanada.org</p>	<p>Niemann-Pick Canada CANADA Established 2017</p> <p>Supporting ASMD and NPC Estimated NPD Patients:</p> <ul style="list-style-type: none"> • ASMD / 10 • NPC / 45 <p> </p>	 <p>Sandy Cowie sandy.cowie@inpda.org</p>
		 <p>Cheryl Marcogliese cherylmarcogliese@outlook.com</p>

We aim to improve what it means to receive a diagnosis of Niemann Pick diseases by supporting medical research to improve understanding of these diseases and improve treatments.

	<p>China Niemann-Pick Disease Foundation CHINA</p>	<p>President Aijun Zhang Jasmine Zhang zhangzhijuan_@126.com</p>
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vml-asso.org

Vaincre Les Maladies Lysosomales (VML)

FRANCE

Established 1990

Supporting ASMD and NPC

Estimated NPD Patients:

- ASMD / >100
- NPC / 80



Zehra Zakiuddin

zakiuddin.iliasse@aliceadsl.fr

Our goal is to offer **help** and **support** to patients and their families, **promote** scientific and medical research. To succeed in these two actions VML focus on communication and fundraising.



niemann-pick.de

Niemann-Pick Selbsthilfegruppe

Deutschland e. V.

GERMANY

Established 1997

Supporting ASMD and NPC

Estimated NPD Patients:

- ASMD / 20
- NPC / 150



Sara Ströer

sara.stoeer@web.de



Lisa Tauszig

lisa.tauszig@yahoo.com

Gather, centralize, and evaluate disease related information and make it available to patients, raise awareness, facilitate clinical trials, networking with patients, clinicians, researchers, and other professionals nationally and internationally.



niemannpick.org

Associazione Italiana Niemann Pick Italy

ITALY

Established 2005

Supporting ASMD and NPC

Estimated NPD Patients:

- ASMD / 40
- NPC / 100



Alberto Lionello

lionello.alberto@niemannpick.org

We have understood that it is necessary to work in team with other realities that deal with rare diseases and disabilities: it's very important to "join the force" to achieve goals that would not be achieved by oneself. We are in contact with INPDA since its foundation. Moreover, we coordinate a regional group called Forum A-rare, formed by 40 associations of rare diseases. We are also in Uniamo (Italian Federation of rare diseases) and Eurordis (European alliance for rare diseases), Telethon, Italian Institute of Health, and many other groups and institutions that fight for patients' right. Our goal is to provide social, human, civil and cultural support, fighting for the rights of Niemann-Pick patients', gangliosidosis, or similar rare diseases. We want to promote the knowledge of these diseases to accelerate the diagnosis timing and allow people to discuss and support each other in patient management. We will at first improve the patients' and families' quality of life. We try to achieve this goal carrying out some project like our Summer Camp (it wasn't possible to do that in 2020 and 2021 because of Covid) that, through the training and the self-mutual aid, it enables families to learn important information on the home management of the patient and to share their own life experience. Other important projects are "My friend probiotic" born to reduce gastric and intestinal problems due to Miglustat and "We'll take care of you" that would improve home care.



stofwisselingsziekten.nl

Volwassenen Kinderen en Stofwisselingsziekten (VKS) NETHERLANDS
Established 1994

Supporting ASMD and NPC
Estimated NPD Patients:

- ASMD / 6
- NPC / 25



Kim Mol
kimr.mol@gmail.com

Our goal is to support people who suffer of inborn errors of metabolism, through information, advocacy and contact with fellow sufferers. Our vision is that people need to be heard and supported, and to level up their quality of life.



Facebook
Niemann Pick i Norge

Niemann Pick Foreningen i Norge NORWAY
Established 2013

Supporting ASMD and NPC
Estimated NPD Patients:

- ASMD / 1
- NPC / 6



Siri Skollerud-Blegen
siriskollerud@yahoo.com

Ensure all families receive support and "have someone" to talk to. Our main focus is on access to trials.



atif@lsdpk.org

www.lsdpk.org
(UNDER CONSTRUCTION)

Lysosomal Storage Disorders Society PAKISTAN
Established 2013

Supporting ASMD and NPC
Estimated NPD Patients:

- ASMD / 60
- NPC / 39



Atif Ejaz Qureshi
atiblue@yahoo.com

Our goal is to establish a sustainable healthcare system in Pakistan whereby all patient patients have access to timely and accurate diagnosis along with access to treatment. We also work to create awareness in general public about life limiting rare disorders and its prevention.



fnp.es

Fundacion Niemann-Pick de España (FNP) SPAIN
Established 2001

Supporting ASMD and NPC
Estimated NPD Patients:

- ASMD / 3
- NPC / 17



Cecilia Bertran Cuní
bertrancuni@gmail.com

We have three goals in our organization: research and the divulgation of the disease, and family attention and orientation. We work every day to achieve our goals, and we are part of different organizations (like INPDA or FEDER, in Spain) because we believe that together will be easier to win this rare disease.



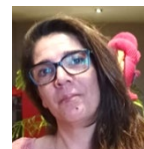
anpf.es

**Asociacion Niemann-Pick Fuenlabrada
SPAIN**

Established 2009

Supporting NPC
Estimated NPD Patients:

- NPC / 16



Salud Guerra Vega
asociacionniemannpick@anpf.es

Our purpose is encouraging scientific research, development, and therapies for NPC disease, together with giving advice, support and information to families affected by the disease. Also, raising awareness in society about the problems NPC causes and promoting stimulating therapies that have an impact on improving the quality of life of NPC patients. And always following our catchword: LET'S KEEP HOPE ALIVE!



asmd.es

**Asociacion Niemann-Pick de Fuenlabrada
(ANPF) ASMD Espana Madrid
SPAIN**

Established 2019

Supporting ASMD
Estimated NPD Patients:

- ASMD / 3



Daniel de Vicente
presidente@asmd.es

Sara de Vicente
secretaria@asmd.es

Our association was created with the aim of seeking and offering solutions to the needs of ASMD patients and their families, always oriented towards improving their health and quality of life. Offering them support and information about the disease, about the health professionals who are experts in it, the possible treatments, and therapies. Improving the visibility of the disease among health professionals, society, institutions, and the public administration, as well as promoting research into ASMD and its possible treatments. To ensure that these treatments reach all patients equally, regardless of their physical or social conditions or their place of residence.

We are committed to a future where ASMD patients have a better quality of life that allows them to lead a normal life with as few limitations as possible. They will have effective treatment that is accessible to all, regardless of the patient's personal and geographical situation.

Health professionals trained in the disease with established protocols for action and monitoring of the disease to reduce the delay in diagnosis and improve the monitoring and treatment of patients.



npsuisse.ch

**NPSuisse
SWITZERLAND**

Established 2011

Supporting ASMD and NPC
Estimated NPD Patients:

- ASMD / Unknown
- NPC / 12



Christoph Poincilit
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Sylvain Schaerli
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The purpose of the NPSuisse association is:

To provide: advice, support and accompaniment to people who are directly or indirectly affected by Niemann-Pick disease.

Inform: the information of those affected, the media, experts, authorities, and the public.

Promote: the promotion of help for self-help, groups of relatives, optimal forms of care and support, training offers - and research.

Fight: representing the interests of those affected to the public, especially politics and the healthcare system.

Networking: the exchange of experiences with patient associations and experts at home and abroad.



tfrd.org.tw/tfrd/home

**Taiwan Foundation for Rare Disorders
TAIWAN**

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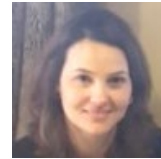


facebook.com/atml.association

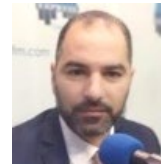
**Association Tunisienne des Maladies lysosomales
TUNISIA**
Established 2018

Supporting ASMD and NPC
Estimated NPD Patients:

- ASMD / 50
- NPC / 6



Ines Bejaoui
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Mouadh Saaid
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The main goals of our association are:

- Raising awareness about lysosomal storage disorders including ASMD and NPC
- Changing the law so that the state recognizes these disorders as chronic diseases.
- Obtaining the treatment for our patients (symptomatic or specific)
- Improving the quality of life of the patients and their families
- Establishing a facility where child patients can have access to education (some of them are not accepted in normal or specialized education establishments due to the fact that they are “different”), and where all patients can receive all the care they need.

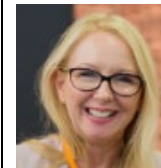


npuk.org

**Niemann-Pick UK (NPUK)
UNITED KINGDOM**
Established 1991

Supporting ASMD and NPC
Estimated NPD Patients:

- ASMD / 35
- NPC / 123



Toni Mathieson
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Jackie Imrie
jackie@npuk.org

Our vision is a world where the burden of Niemann-Pick disease is minimized, where those affected have access to effective therapies, are able to meaningfully participate in society, reach their full potential and achieve the best quality of life possible.

NPUK is a charitable organization dedicated to making a positive difference to the lives of those affected by Niemann-Pick disease and their families, from diagnosis to bereavement and beyond. We raise much needed awareness, provide practical and emotional support, advice and information, and facilitate research into potential therapies.

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, through the provision of a wide range of activities in three key areas: Care and Support, Information and Research.



theholliefoundation.com

**The Hollie Foundation
UNITED KINGDOM**
Established 2014

Supporting NPC
Estimated NPD Patients:

- NPC / 100







Helen Carter
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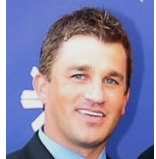






Diane Waller
diane@theholliefoundation.com

Our mission is to make the lives of those affected by NP-C today a little easier whilst working collaboratively towards finding a viable long-term treatment or therapy.

We support families and other organizations working in the NP-C field through our grant giving program, providing funding for research, specialist equipment, the enhancement of vital support services and other social and medical needs. We also work to increase knowledge, education, and awareness of all aspects of NP-C

 <small>NATIONAL NIEMANN-PICK DISEASE FOUNDATION, INC.</small> nnpdf.org	National Niemann-Pick Disease Foundation UNITED STATES Established 1993 Supporting ASMD and NPC Estimated NPD Patients: <ul style="list-style-type: none"> • ASMD / 100 • NPC / 300 	 Joslyn Crowe jcrowe@nnpdf.org
		 Becky McGuire bmcguire@nnpdf.org
<p>The National Niemann-Pick Disease Foundation, Inc. (NNPDF) is a non-profit patient advocacy and family support organization dedicated to supporting and empowering patients and families affected by Niemann-Pick disease, through education, collaboration, and research. Founded in 1992, NNPDF serves families throughout the nation at all stages of their Niemann-Pick journey.</p>		

 WylderNation.org	Wylder Nation UNITED STATES Established 2013 Supporting ASMD 	 Steven Laffoon steven@wylderNation.org
<p>Accelerate the discovery and development of treatment options for ASMD, specifically to address the significant unmet needs regarding the neurological manifestations of the disease.</p>		

 <small>SHINING A LIGHT ON NPC1</small> fireflyfund.org	Firefly Fund UNITED STATES Established 2017 Supporting NPC 	 Pam Andrews pam@fireflyfund.org
		 Chris Andrews chris@fireflyfund.org
<p>Our mission is to fund and support the research and education necessary to accelerate a cure for rare neurodegenerative genetic diseases that affect children and currently have no cure. We have begun our journey with a focus on Niemann-Pick Disease Type C.</p>		