

# Mandos Health

## February 2024 To the NPC1 Community,

We are excited to share important updates on our progress and commitment to supporting the Niemann-Pick Type C (NPC) Disease. Here is the overview of topics we cover in this newsletter:

1. Community Update
2. Rare Disease Day
3. Development Program Update
4. Expanded Access Program

### Community Update

Recently, Mandos attended the 2023 INPDA Face to Face meeting in Tarragona Spain November 10-12, 2023, which was hosted by Fundación Niemann Pick de España. The meeting demonstrated the incredible progress of the NPC community. Over one hundred attendees representing NPC research, foundations, industry, caregivers, and families attended the conference. HOPE WINS was the conference theme in honor of those who have lost their battle with NPC disease.

Mandos was proud to support and connect with all facets of the NPC community to advance the research and development of adobetadex (VTS-270) for patients living with NPC.



*INPDA 2023, Tarragona, Spain*

Mandos will be attending and sponsoring the [2024 Parseghian Fund Annual Conference](#) on June 8-11, 2024 in Tucson, AZ, and the [NNPDF Family Support & Medical Conference](#) on July 11 – 13 in Salt Lake City, Utah.

## Rare Disease Day



Mandos Health is excited to participate in [Rare Disease Day 2024!](#)

We will be sharing our colors and participating in patient speaker series and patient stories to help raise awareness and educate our teams about generating change for the 300 million people worldwide living with a rare disease, their families and carers.

Rare Disease Day this year is on Thursday, February 29th.

### Development Program Update

We continue to drive forward our plans to support a laser-focused evaluation of clinical, biomarker, natural history, and real-world data for the VTS program. This analysis will be the first of its kind in NPC.

We are getting closer to finishing our assessment and we intend to begin writing publications and sharing our data findings with the NPC community and thought leaders after we receive advice from the regulatory agencies.

We know every day matters. We couldn't be more grateful for the trust you continue to place in us.

### Expanded Access Program (EAP) Update

We remain steadfast in our commitment to the EAP. Recently, we invested in securing an additional drug product manufacturing site which allows continued supply of VTS-270 through 2025.

Mandos Health would also like to thank those sites who continue to provide expanded access and care to the NPC patients and their families.

### Stay up to date with our progress

We are committed to continuing to build a science-driven organization dedicated to NPC.

We enjoy engaging all stakeholders with updated communications through conference attendance and patient advocacy organization meetings.

Stay up to date with us at [www.mandoshealth.com](http://www.mandoshealth.com)

*\*Adrabetadex is an investigational drug that has not been approved by FDA, and FDA has not found it to be safe and effective for use to treat NPC1 or for any other use.*

# Mandos Health

**A world of support for all affected by NPC1**

Research. Access. Collaboration.

#NoStoneLeftUnturned #TheRightThingToDo #BuiltForPatients

© 2024 Mandos, LLC.

Mandos Health · Mandos, LLC · Los Angeles, CA - · USA