

# HD News

AUTUMN  
2023



*Ailsa's*  
**LEGACY**  
Huntington's NSW ACT's  
HD Education Scholarship

**5**  
**HA UPDATE**  
Meet the CEO  
Lenni Duffield

**6**  
**RESEARCH**  
Roche Phase II  
study underway

**7**  
**COUNSELLING**  
We launch our  
new service

## AILSAS'S LEGACY 2023 - HD YOUTH EDUCATION SCHOLARSHIP

APPLICATIONS  
NOW OPEN

**WORDS** AMY HALE

We are excited to announce that applications for the 2023 Ailsa's Legacy Youth Scholarships are now open and invite all children and young people in our HD community needing assistance to start, continue, or return to education in 2023 to apply.

We have a number of individual grants available this year of up to \$2000 each for children and young people living with an HD affected parent or carer. These grants can be spent on anything that makes accessing education easier and more likely such as course or school fees, uniforms and shoes, computers, IT and software, school camps, school sports, extra tuition,

extracurricular activities, transport, accommodation, and more.

We would like to encourage as many children and young people as possible to apply. We understand how important it is to stay engaged in education, but also know how challenging this can be when there is a lot more going on at home such as taking on extra responsibilities, stretched finances, and often less time to study and prepare, as can often be the case when a parent or carer is affected by HD.

If you can answer yes to the following 5 questions, you are eligible to apply.

- Are you under 25?

- Are you enrolled in school, university, TAFE (or another educational institution) or planning to be, in 2023?
- Are you living with an HD affected parent or carer (or have previously done so)?
- Do you live in NSW or the ACT?
- Would receiving this grant help you start, continue, or return to education in 2023?

**You will find our Ailsa's Legacy FAQ booklet and application forms on our website [www.huntingtonsnswact.org.au](http://www.huntingtonsnswact.org.au) If you are not online, please phone our office on (02) 9874 9777 and we can mail this information to you.**

(continued on page 2)

## WHO IS AILSA?

Ailsa was smart, funny, creative, spirited, and curious. She loved to learn and found her purpose in sharing this gift with others. Ailsa believed in the power of education. As a dedicated teacher with a passion for helping children grow through learning, she saw first-hand the opportunities education can provide for a young person to imagine and create a life of potential well beyond whatever difficulties they were experiencing.

Ailsa also knew Huntington's disease. When she was a child, her dad developed HD - a disease she would unfortunately go on to inherit. Growing up with HD in the family, Ailsa and her sister experienced how challenging it was to stay motivated, resourced and engaged in education when everyone in the family was struggling with HD in their own unique way.

This education grant program has been generously funded by an anonymous benefactor who knew and loved Ailsa; to honour Ailsa's commitment to the welfare and education of young people, to recognise her understanding of how challenging it can be growing up in a family affected by HD, and to celebrate the creativity and courage with which Ailsa managed her own HD diagnosis.

Ailsa's Legacy has been created in memory of Ailsa to help young people affected by HD on their journey towards everything an education can bring.



## FROM THE DESK

*Lewis Kaplan*

### LEWIS KAPLAN, CEO

#### Huntington's NSW ACT

##### **Merger**

As the Huntington's Australia merger gathers pace, we have been lucky to receive two visits in January and March from the new national CEO, Lenni Duffield, who is based in Perth (and was the CEO of Huntington's WA before her national appointment). Most staff will be offered similar jobs in the new organisation, with some having the opportunity to apply for a promotion to more senior roles. Each of the merging states are working to support the process, with a number of staff in NSW taking on additional duties to smooth the way.

##### **NDIS**

Our NDIS service continues to grow, although we were sad to farewell our inaugural Support Coordinator, Giselle Beaumont in February. Giselle set the service up in July 2019 and continued to grow the client base right through COVID-19, working incredibly hard to meet the complex needs of those with HD who chose us to provide their NDIS support coordination. We now have the equivalent of nearly 4 full-time NDIS staff and have just submitted our application to start offering counselling and behaviour support under the NDIS in addition to support coordination services. This may take a while to come through as the NDIS Quality and Safeguards Commission is under-resourced and overwhelmed with work.

##### **NSW government funding**

We continue to advocate to the NSW Government to provide more funding

than the current contribution by NSW Health of \$68,000 per year. As a matter of interest, the Huntington's Association in Western Australia is relatively well funded compared to other states. If NSW received state government funding to the same level per capita of people with HD here, we would receive around \$1 million per year! This would be a big increase, one that would help our HD community tremendously with support and services. Are you able to help advocate with us?

##### **Younger people in nursing homes**

We have been closely following the saga of younger people with HD living in residential aged care homes. The most recent numbers released under an FoI request show a steady decline in the number of people with HD under 65 years old in aged care. There are now only four people with HD under the age of 45 living in aged care – all in Victoria; and only 12 people with HD in aged care between the ages of 45 – 64, of whom 5 in NSW and 4 in Victoria. The assumption is that people are instead being accommodated in residential disability care homes, which means that they are likely to be receiving under the NDIS many multiples of the maximum funding that would be available in aged care. The question of their access to quality care and nursing services within disability care remains one which is not yet fully answered, and we expect this will continue to change (and we hope improve) over coming months and years.



# ALL THINGS NDIS

## WORDS MALISHA FERNANDO

The year 2023 has well and truly started and there are a few updates we would like to share from our NDIS Support Coordination team.

Giselle Beaumont, who started Support Coordination services with Huntington's NSW ACT 3 years ago has finished up her role and moves on to new adventures but will still be linked to clients needing support under therapeutic supports. We would like to extend our extreme appreciation for the many years of service and hard work it has taken for Giselle to build up an NDIS Support Coordination service that supports NDIS participants in the community.

The role Giselle held covered a large scope of responsibility including billing, management, building relationships with external services, support coordination and specialist support coordination. This role has now been split, where we will have Senior Support Coordinator oversee management functions and support coordination and another role dedicated to Specialist Support Coordination which will provide support to our more complex participants.

Following this, recruitment has been underway, and we are pleased to announce that we are onboarding our new Specialist Support Coordinator during March and eagerly await their introduction to our NDIS Support Coordination participants in near future. In addition to this, the team welcomes a new Support Administrator to assist the NDIS team with administrative functions.

In terms of NDIS news, NDIS appears to be going through a number of significant changes over the next 12 months. Namely a new business software called "PACE" that will be

trialled in Tasmania over the next 3 - 6 months before rolling out nationally (if successful). Based on information available, PACE will replace current NDIS portal and payment systems for providers so that they are more user-friendly. This will not impact the service NDIS clients receive, but more so the PACE system will allow providers to spend less time navigating the portal to complete basic tasks.



### WELCOME *Mia*

Mia has worked as a Specialist Support Coordinator in the NDIS space for the past 5 years. Mia's background is in Social Work and she has managed many complex and challenging cases with the NDIS. As a social worker, Mia has a strong advocacy and report writing background which has yielded significant successful outcomes for her NDIS participants.



### WELCOME *Justine*

Justine works within our support coordination team to provide administration support. Justine has previously worked in the aged care sector in administration, with her last role in a multidisciplinary allied health clinic. She is currently completing a Certificate IV in Community Services and is eager to be involved in the HD community.

## HIGH TEA 4 HD

With the High Tea 4 HD being a big success in 2022, we have decided to run the events again in May. Please put the dates in your diary and help us to share them with as many friends, family members and colleagues as possible. We'd love to see you there.

- Sunday 7th May - Penrith
- Sunday 14th May - Orange
- Sunday 21st May - Newcastle

**Further information and tickets will be available shortly. Please check our socials and our website for more information.**



<https://huntingtonsnswact.org.au/events/high-tea-4-hd-2022/>



## CHRISTMAS WRAPPED UP

Our Christmas appeal went out in early December and together people donated **\$7,282** for the appeal. We would like to say thank you to each person who donated, together we are making a difference to our community. Your continued generosity allows us to support people and families affected by HD.

## A GIFT OF HOPE

**Have you made a Will? Is your Will up to date?**

A gift in your will is a gift of hope that allows you to make a difference in the fight against Huntington's disease beyond your lifetime. We need your help to ensure that we can keep on being the voice for current and future generations of families facing Huntington's disease.

Our goal is to continue to reach out and be there in those tough times when everything may seem so hopeless. Lobbying government, providing support and education, and raising awareness to remove the social isolation and fear for families who have been impacted by Huntington's disease. Leaving something behind is a lovely legacy that can help others.

**For more information or to obtain a copy of our Gift of Hope flyer please email [info@hdnswact.org.au](mailto:info@hdnswact.org.au) or call the office on 9874 9777.**

# CEO APPOINTED FOR HUNTINGTON'S AUSTRALIA

**WORDS** CHRIS GLASSON, CHAIR HA

Huntington's Australia is excited to announce the appointment of our new CEO! Lenni Duffield from Huntington's WA has been unanimously endorsed by the Huntington's Australia Board as the inaugural CEO of Huntington's Australia.

Lenni has held senior roles and provided business consulting services in health and community service sectors, has qualifications in business, management and leadership, community sector management and is currently in the process of completing her Master in Business Administration with the Australian Institute of Management, with whom she is an Associate Fellow.

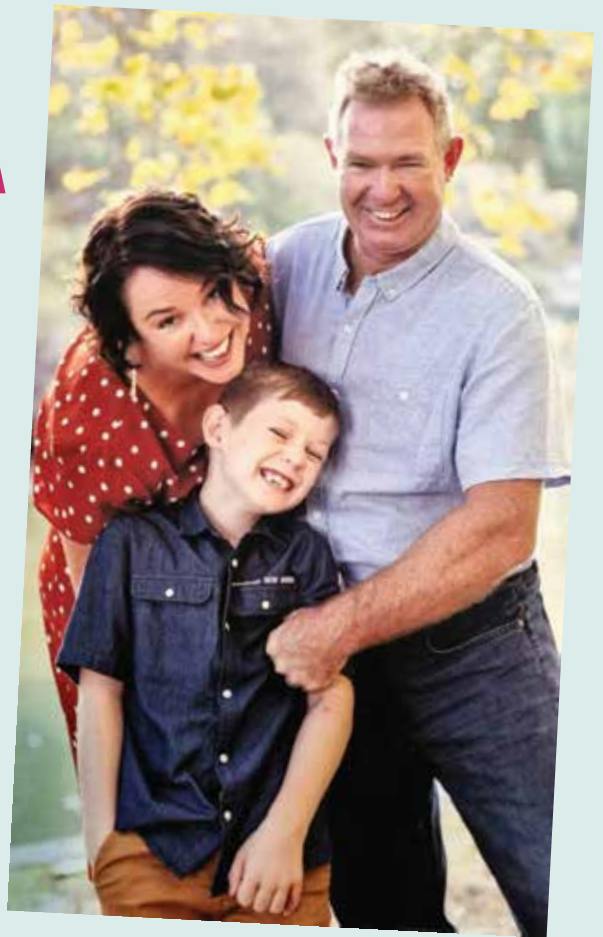
Lenni comes equipped with a range of skills, knowledge, qualifications, experience and personal attributes that make her a standout candidate. Her commitment to and passion for bettering the lives of people with and impacted by Huntington's disease is unquestioned.

Fortunately for us, we have been able to see what Lenni can do in person over a good period of time, through her work as CEO in WA and thorough her Project Management work with the merger feasibility study and more latterly planning for the merger implementation. Her consistent, high quality work and standards over an extended period of time give us great confidence that we have the right person to take the new organisation forward.

This is a proud and momentous occasion in the thus far very short history of Huntington's Australia. The Board has confidence that Lenni will lead us into a better future for our Huntington's communities.

Regards

**Chris Glasson**  
Chair HA



*"This is my family, myself, my husband Adam and our gorgeous son Lawson. We are a busy little family juggling working life and living on a working property looking after a menagerie of farm animals, it's always hectic with something to do, but we love it! We have fruit trees, grow veggies and run our own sheep. I'm fiercely passionate about the for-purpose sector and championing the roles and vital contributions that organisations such as the HD state associations and Huntington's Australia contribute to communities and the government. When I'm not doing the work I love, I'm in the garden (a labour of love), or entertaining friends and family at home when not studying for my MBA or volunteering on local community projects. Also, when time permits I love being creative!"*

## HD ID CARD

We are often asked if we have any ID cards for people to carry – and the answer is yes. If you'd like us to send you out cards, please contact the office.

### MEDICAL IDENTIFICATION

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Phone: \_\_\_\_\_

I have been diagnosed with  
Huntington's Disease (HD)  
see over for details





# ROCHE PHASE II GENERATION HD2 STUDY UNDERWAY

**SOURCE** HD BUZZ

**WORDS** DR RACHEL HARDING

Roche released a community letter last month, detailing how their Phase II clinical trial to study the huntingtin-lowering drug, tominersen, is now underway. Learn more about what this means in this article and at the recent HDSA Research Webinar, with representatives from the company.

## THE UPS AND DOWNS OF HUNTINGTIN-LOWERING

Tominersen is a type of drug called an ASO, which aims to lower levels of the huntingtin protein, and is delivered through spinal injections. People with Huntington's disease make an expanded form of the huntingtin protein, due to an expansion in their huntingtin gene. By reducing the amount of the expanded huntingtin protein, scientists working on these drugs hope they might slow or halt the progression of symptoms of Huntington's. Many companies are working on huntingtin-lowering using different types of drugs, including Roche, Wave, uniQure, and PTC therapeutics.

The path of tominersen from the research lab to this most recent clinical trial has certainly been a bumpy one. A study of tominersen which concluded in 2019 was the first to show that it was possible to lower levels of the huntingtin protein. It also appeared to be safe in people for the duration of the 3-month trial. In a subsequent Phase III trial, called GENERATION HD1, more than 800 participants were enrolled to test if tominersen might improve signs and symptoms of Huntington's. Unfortunately, GENERATION HD1 was cut short due to safety issues. We still don't fully understand the reasons for this, but participants who received the highest and most

frequent dose of the drug did worse by many measures than patients who were given the placebo, the exact opposite of what we had hoped for.

Roche scientists then spent a long time poring over all the findings from GENERATION HD1 and uncovered some trends suggesting that tominersen may have benefitted some trial participants, especially those who were younger and began the trial with less prominent symptoms of HD. This type of analysis where scientists pick back through subsets of the data is called "post hoc". The original GENERATION HD1 study was not designed to answer the question of whether the drug is better for this category of Huntington's patients, but there does seem to be a potentially promising pattern. To address this question properly, Roche scientists need to run another clinical trial and this is how GENERATION HD2 came about.

## GENERATION HD2 - A FRESH APPROACH TO QUESTIONS ABOUT TOMINERSEN

This new trial will try to answer a few different questions about the possibility of using tominersen as a treatment for Huntington's, focusing on the safety of the drug and whether it's properly hitting its target (huntingtin).

- First, scientists will hope to answer if lower doses of tominersen are safe as a long-term treatment for this younger, less progressed subgroup of Huntington's patients. As with previous trials, lots of different measures will be taken to check for participant safety.
- Second, they will investigate if tominersen has impacts on

biomarkers of Huntington's, things that can be measured in blood or spinal fluid to get a picture of brain health. This will include a protein called NfL, levels of which go up in people suffering symptoms of neurodegenerative diseases.

- Thirdly, they will assess how well the drug is hitting its target in this more focused patient group. This will include a measure of the huntingtin protein itself, which we expect to be lowered, as we have seen in previous tominersen studies.
- Lastly, they'll also look at how tominersen affects people's thinking, movements, and behaviour.

Everyone recruited into this trial will be randomly assigned to one of three groups, where they will either receive a low 60 mg dose of tominersen, a higher 100 mg dose of tominersen, or a placebo dose. Both doses are lower than the 120 mg tested in GENERATION HD1. As per previous tominersen trials the drug will be given by spinal tap, but in this trial, everyone will receive their dose every 4 months for a total of 16 months of treatment and monitoring. Data collected will be assessed approximately every 4 months by an independent data monitoring committee (iDMC) which will monitor the trial safety and look at the clinical and biomarker data to see how things are progressing. This is confidential, unless there are serious issues, and completely independent of Roche's own analysis of the data which will happen when the trial ends.

## WHO WILL BE ENROLLED INTO THIS NEW TRIAL?

This new trial will last 16 months, and approximately 360 participants

will be enrolled. To follow up on their post hoc analysis from GENERATION HD1, this study will be enrolling participants aged 25-50 years old who have only the very early signs of Huntington's. You may have read the terms "prodromal" or "early manifest," which is the science-y way doctors and researchers refer to people with Huntington's right around the time that movement symptoms appear.

The study will take place across 4 continents with sites in 15 countries spread across North America, Europe, South America and Oceania. Precise information about the sites will become available once they are each approved and will be posted on clinical trial directories such as [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (global) and [www.hdtrialfinder.org](http://www.hdtrialfinder.org) (North America), but sites are expected in Argentina, Austria, Australia, Canada, Denmark, France, Germany, Italy, New Zealand, Poland, Portugal, Spain,

Switzerland, UK and the USA. Each site may have slightly different rules about participant recruitment i.e. how close to the site you need to live to be considered for enrollment, and not all of the sites from previous tominersen trials will participate in the GENERATION HD2 trial. Keep in mind that most clinical trials recruit through strong relationships between doctors and patients.

Those individuals who were previously in a trial testing tominersen would only be eligible for enrollment in GENERATION HD2 if they had received the placebo dose. Roche stated that their decision to exclude individuals who previously received tominersen was not made lightly, and was made "following extensive consultation with HD experts and community leaders." This news, and the narrower age range for eligibility, may be very disappointing for some. But Roche is committed to answering important safety questions about tominersen, based on previous

data. Although this trial will focus on younger people with less advanced HD symptoms, Roche emphasised that they have not forgotten the complete range of patients which comprise the HD community, nor the commitment of previous participants, and there may be other opportunities for these folks in future.

### HOW CAN I LEARN MORE ABOUT GENERATION HD2?

Roche participated in an HDSA Research Webinar last week where more of the specifics of the trial were discussed, including the precise criteria for participant enrollment and members of the Huntington's community put their own questions directly to the scientists at Roche. You can rewatch this webinar here <https://www.youtube.com/watch?v=yISrvby5uy8> until early April, 2023. Stay tuned on HDBuzz for more news as things progress.



## WE LAUNCH OUR HD COUNSELLING SERVICE

After consultation with our team and Prof. Clement Loy, Director of the NSW Huntington's Disease Service and his team at Westmead Hospital, we have created a specialist Huntington's disease counselling role supporting people with early to moderate Huntington's disease. The need for specialist counselling has been articulated by our NDIS team and Youth Social Worker as well as by the multidisciplinary team at Westmead which does not have such a position in its staffing complement.

We would like to acknowledge The Co-Group for their commitment to fund this project. We are very excited to launch this service to help the community deal with challenges in a positive way by helping clients to work through issues, explore options, create strategies and enhance self-awareness.

Julie Leto has recently joined us to fill our new and exciting Specialist HD Counsellor part time role. Some of you will remember Julie from her time working with HNSW ACT from 2016 - 2018 as our Rural and Regional HD Social Worker.



WELCOME

*Julie*

As a qualified Social Worker, Julie is an advocate for people with a disability and has strong social justice principles. In her four years away from us Julie has maintained her passion for working with the Huntington's community and now brings with her even more experience and knowledge through completing a Master of Family Studies and a Master of Counselling and Psychotherapy.



# Huntington's NSW ACT

Huntington's NSW ACT Inc.  
PO Box 178, West Ryde, NSW 1685  
21 Chatham Road, West Ryde, NSW 2114

Telephone: (02) 9874 9777  
Free Call: 1800 244 735 (Country NSW only)

Email: [info@hdnswact.org.au](mailto:info@hdnswact.org.au)  
Web Site: [www.huntingtonsnswact.org.au](http://www.huntingtonsnswact.org.au)

## Our team

### LEWIS KAPLAN

Chief Executive Officer  
0407 108 667

### MALISHA FERNANDO

NDIS Senior Support  
Coordinator

### MIA SMALL

NDIS Specialist Support  
Coordinator

### KATE MCNAMARA

NDIS Support Coordinator

### JUSTINE AMOS

Support Services Administrator

### AMANDA DICKEY

Community Programs Officer  
0456 013 612

### AMY HALE

Youth Social Worker  
0499 031 231

### STEWART SWALES

Administration Co-ordinator

### ALISON WEIR

Fundraising & Marketing  
0419 465 612

## HD SERVICE

### Westmead Hospital

#### DR CLEMENT LOY

(DIRECTOR), DR SAM KIM,  
DR FLORENCE CHANG  
Neurologists  
(02) 8890 6793

#### FELICITY STEHOUWER

Social Worker  
(02) 8890 6699

#### SANDRA BARISIC

Clinical Nurse Consultant  
(02) 8890 9960

#### PETER KWONG

Clinical Nurse Specialist  
(02) 8890 9960

HD Clinic Appointments  
Outpatients Department  
(02) 8890 6544

## HUNTER HD SERVICE

### John Hunter Hospital

#### JOHN CONAGHAN

Social Worker  
(02) 4922 3076

## HUNTINGTON'S UNIT

### St Joseph's Hospital

(02) 9749 0215

## PREDICTIVE TESTING

Find your nearest Genetics  
Clinic at <https://www.genetics.edu.au/SitePages/Genetic-Services.aspx>

## EDUCATION RESOURCES

### Huntington Study Group

Global HD cooperative  
therapeutic research org.  
<https://huntingtonstudygroup.org>

### HDYO

Support and education to  
young people (aged up  
to 35) impacted by HD  
around the world.  
<https://en.hdyo.org/>

## RESEARCH QUERIES

### Dr Therese Alting

Enroll-HD Study  
(Westmead Hospital)  
(02) 8890 6310 or  
0438 604 719

### HDBuzz

Research news. In plain  
language. Written by scientists.  
For the global HD community.  
<https://en.hdbuzz.net/>

### Huntington's Disease Network of Australia (HDNA)

The map-HD registry.  
(03) 9902 0081  
<https://hdna.com.au>

# WHAT'S HAPPENING? COMMUNITY SUPPORT GROUPS



Take a look  
at how your  
region is  
choosing to  
connect.

## PEOPLE LIVING WITH HD SUPPORT

### WOLLONGONG (Social)

Wollongong, 11:30am – 1:30pm  
1st Monday monthly.

## CARER SUPPORT

### CENTRAL COAST

Postponed until a facilitator is recruited.

### COFFS HARBOUR

Korora, 11:00am - 1:00pm  
3rd Friday monthly.

### NEWCASTLE

Jesmond, 10:00am - 12:00pm  
2nd Thursday monthly.

### SYDNEY

Postponed until a facilitator is recruited.

### Online Carer Support group (metro and regional)

Postponed until a facilitator is recruited.

## COMMUNITY SUPPORT

### ACT (Social)

Ainslie, 11:30am - 1:30pm  
1st Saturday bi-monthly.

### ORANGE & CENTRAL WEST (Social)

Quarterly  
Details to be confirmed, refer to our website.

### PORT MACQUARIE

Northhaven, 11:30am – 1:30pm  
1st Thursday bi-monthly  
April 6th, June 1st

### Latest details and to register your

interest can be found on our website at:

<https://huntingtonsnswact.org.au/support-groups/>  
or contact us on 02 9874 9777.