



# Ailsa's LEGACY

Huntington's NSW ACT's  
HD Education Scholarship

**HD YOUTH  
EDUCATION  
SCHOLARSHIP  
INFO & FAQ**





“The more that you read,  
the more things you will know,  
the more than you learn,  
the more places you’ll go”

– Dr Seuss



# AILS GORDON:

Teacher, psychologist, HD family member & education advocate

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 kids grow through learning, she saw first-hand the opportunities education can provide for a child 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 in 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.







# WHAT IS AILSA'S LEGACY?

Ailsa's Legacy is an annual educational scholarship. Each year a number of individual sums of money (up to \$2000 each) will be given to successful Ailsa's Legacy applicants.

This scholarship has been set up to provide financial support for young people in families affected by Huntington's disease (HD) to start, continue, or return to education.

The payments can be used for education or training in a range of ways. These might include:

- uniforms and shoes
- course or school fees
- course work materials
- computers and software
- school excursions
- school camps or trips
- transport
- accommodation
- emotional support/counselling
- extra tuition
- extracurricular activities
- sports uniforms and equipment.





# HOW DO I KNOW IF I AM ELIGIBLE TO APPLY?

To be eligible to apply for an Ailsa's Legacy scholarship, you must:

- Live with and/or care for a person with a diagnosis of HD or have done so previously (*In the case of a person with HD living in residential care, or outside the home or if your HD family member has passed away you are still eligible to apply*)
- Be under 24 years old for the entire time you are receiving the scholarship - at the time of application
- Reside in NSW or the ACT for the entire time you are receiving the scholarship
- Be studying, or in the process of applying to study, at school, TAFE, university, or another recognised education institute.

# WHY SHOULD YOUNG PEOPLE FROM HD AFFECTED FAMILIES APPLY?

Balancing education with the extra challenges living with a Huntington's disease (HD) affected parent or carer can be hard.

For someone in this situation, life is often more challenging than it is for the majority of young people. It might be more difficult to stay engaged in school, TAFE, or uni as they take on the physical, emotional, and logistical challenges HD throws their way. There can be caring responsibilities for a parent with HD, extra work managing siblings and home life, financial stress and/or disadvantage, emotional stress around the disease, and often a lack of practical carer support for a young person that helps to make prioritising education possible.

Whether they are struggling to find a quiet space to learn, trying to find a balance between caring for a parent with HD and learning, these factors can make for a harder path to education.



# HOW DO I APPLY?

Visit the Huntington's NSW ACT website Youth Connection Program page and follow the links to this year's application form.

If you are not able to apply in this way and or would prefer to apply via meeting or over the phone, please please call our office on (02) 9874 9777 to talk to someone about other options for applying.





# WHAT TYPES OF QUESTIONS ARE IN THE APPLICATION?

The application asks questions about you, your intention to study and the impact HD has in your life. This will include:

- Who has an HD diagnosis in your family?
- How long they have had HD?
- What impact has this has on your ability to access or stay involved in education?
- What you intend the money to go towards

Please answer these questions clearly and with as much information as possible so the people reviewing your application gets an understanding of your life, how HD impacts this and how this money will help you.









# FREQUENTLY ASKED QUESTIONS

01

## How much can I apply for?

You can apply for a one-off payment of up to \$2000.

02

## What documents will I need to provide?

To make an initial application for the Ailsa's Legacy, you do not have to provide us with any documents - just complete and submit the application form.

If your application is successful, you will be asked to provide the following documents to receive payment. At this time, you will be instructed on how to provide these documents for us to check.

### **Proof of age, identity and Australian residence using ONE of the following:**

- Australian Driver's License
- Australian Birth Certificate
- Australian Passport
- Proof of Age card
- Student ID card

### **Proof of current enrolment in School, TAFE or University and residency in NSW or the ACT using ONE of the following:**

- Signed form from school/TAFE/University professional (we will provide this form for you if you are shortlisted)
- Current Student ID card.

# 03

## **What if I am under the age of 18?**

If you are under 18 you can fill out an application form and submit it without your parent or guardian's permission. If you are shortlisted, we will ask for your parent/guardian consent at that time.

An exemption can be applied in exceptional circumstances. Please contact Huntington's NSW ACT if you are under 18 and you are not able to get parent or guardian permission, or if obtaining this permission will put you at risk in any way.

# 04

## **What happens if I do not have my own bank account?**

Ideally, payments should go directly into your bank account however, if you are not able to get an account, you can nominate to have this paid into a parent/guardians account.

# 05

## **I am not sure if I will be returning to study next year, should I still apply**

Yes. If you do not return to study, you can always withdraw your application at any time.

# 06

## **Is the Ailsa Legacy income tested?**

No.



07

## **How many years can I apply for the Ailsa Legacy?**

You can continue to apply each year if you remain eligible.

08

## **Can other family members in the same household apply too?**

Yes, we encourage everyone to apply that meets the eligibility requirements, even if you are all caring/living with the same family member with HD.

09

## **Can I apply if I am receiving a government carers allowance, carers payment or other payments from the NDIS?**

Yes.

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## **What if I am late to apply and miss the deadline because something challenging has happened at home, at school or with my application?**

It is possible your application can still be considered. This will be decided on a case-by-case basis. If you have missed the deadline, please contact the Huntington's NSW ACT to discuss this.

# 11

## **Can my support worker, teacher, family member/carer, friend or other professional help me with my application if I require this?**

Yes. We understand completing an application can be tricky and we encourage you to get whatever help you need in applying for this bursary and gathering the required documents if you are successful.

If the person helping you needs further information to assist you, please get them to contact Huntington's NSW ACT.

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## **Can my support worker, teacher, parent, friend or health professional be listed as an extra contact person on my application if I need this?**

Yes. If this person is over 18 years old and you list them as an extra contact person on your application, both yourself, and the adult listed will be able to enquire about the progress of your application and receive emails or phone calls from Huntington's NSW ACT about this application.

We will not provide personal information about you to them or tell them what you have written in your application. Verbal or written consent is required for this to occur. Please contact the Youth Services Practitioner to discuss this if you would like more information.



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## **Who will see my application and who will decide what applicant gets a scholarship?**

The Huntington's NSW ACT Board (meaning the group of people responsible for making sure Huntington's NSW ACT is operating well, safely, and legally) will establish an assessment panel each year to read all applications and decide together who will receive a scholarship. This will be discussed by the panel and will be based on the applicants that the panel decides are most in need of this assistance.

The benefactor (meaning the person who generously donates this money each year) has an ongoing invitation to be in this panel.

A young person affected by HD will also be in this panel. This young person will bring a first-hand perspective to the panel to help them with their decision.

The Huntington's NSW ACT CEO (the boss of the organisation), and the Huntington's NSW ACT Youth Services Practitioner will be allowed to read the applications and speak to the panel members but will not be able to decide which applicants receive these bursaries.

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## **How do I know the information I put in my application will be kept private?**

Only the people selected to be on the panel, and those with special invitations to sit with the panel, will be able to read your application.

All of these people are required to sign a Non-Disclosure Agreement (sometimes called an NDA or a Confidentiality Agreement) - this is an agreement stating that they will keep all of the information they read in your applications private. They must not tell anyone who is not on the panel what they read. This is a legal document designed to make sure the private information you tell us in your application is kept safe and not shared to others.

The only reason this confidentially agreement can be broken is if an application contains information that indicates you or someone else is at risk of serious harm. If this occurs, the Huntington's NSW ACT team will contact you to help find ways to make sure everyone is safe and may also be required to contact child protection or emergency service agencies to ensure safety needs are met.

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## **What are my responsibilities once if my application is successful and I receive the scholarship?**

For your application to be successful, we ask that you complete TWO short surveys - one in the middle of the year, and one at the end of the year. These surveys will contain questions about how you have used your bursary money and whether receiving this money helped your or did not help you achieve what you wanted to achieve.

These surveys can be completed in writing or by speaking with the Youth Services Practitioner.

We would also like you to participate in a short interview with a member of the Huntington's NSW ACT Youth Connection Program team about your experiences of receiving this scholarship. This interview will go into an article in the Huntington's NSW ACT Newsletter at the end of the year. You can remain anonymous or chose to have your name published. This will be entirely up to you.

# 16

## **What happens if my application is not successful?**

We understand that there are many young people affected by HD in need of assistance. Unfortunately, we only have a limited number of scholarships available each year. If you are not successful this time, please apply again next year.

# 17

## **What if I need to talk to someone about HD? Can I get help?**

Yes. Whether or not you are interested in, or eligible for this bursary, our Youth Services Practitioner can help you.

Please contact the Huntington's NSW ACT Youth Connection Program if you need support, counselling, assistance, or would like to meet other young people in similar circumstances. All support provided is at no cost and is available all year.