

# A GUIDE TO THE STEVE WAUGH FOUNDATION AUSTRALIA **INDIVIDUAL GRANTS APPLICATION FORM 2010**



**THIS APPLICATION FORM IS FOR INDIVIDUAL ASSISTANCE AND NOT FOR PROJECTS, PROGRAMS OR RESEARCH.**

THE STEVE WAUGH FOUNDATION IS COMMITTED TO A CO-ORDINATED APPROACH TO THE IDENTIFICATION, TREATMENT AND RESEARCH OF RARE DISEASES IN AUSTRALIA.

## **WHAT IS THE STEVE WAUGH FOUNDATION AUSTRALIA?**

- The Foundation is a registered Charity in Australia.
- The Foundation is committed to a coordinated approach to the service, identification, treatment and research of rare diseases to improve the quality of life of children/young people affected by rare diseases (0-25 years of age).

## **OUR PHILOSOPHY**

- We recognise due to resources and financial limits we will not be in a position to support all individuals, family and community needs in the area of rare diseases. Our philosophy is to support rare diseases that are unable to get support from other sources.

## **CRITERIA FOR FUNDING**

- Applicants must be between the age of 0-25 (applicant must not turn 26 in the year the application is submitted).
- Be an Australian citizen or Permanent Resident of Australia.
- Have an Australian Medicare Card.
- Have a recognised rare disease as identified on ORPHANET (An International recognised list of rare diseases and reference for medical health professionals) Refer to [www.orpha.net/orphacom/cahiers/docs/GB/Prevalence\\_of\\_rare\\_diseases\\_by\\_alphabetical\\_list.pdf](http://www.orpha.net/orphacom/cahiers/docs/GB/Prevalence_of_rare_diseases_by_alphabetical_list.pdf).

- The rare disease has been formally and officially diagnosed by a Paediatrician and/or Geneticist, and has a name.
- You have and can provide evidence of the diagnosis of the rare disease signed off by a Paediatrician or Geneticist.
- You have and can provide medical, health and other documentation or support material required as part of this application.

## **DO I HAVE TO BE AN AUSTRALIAN CITIZEN TO GET SUPPORT FROM THE STEVE WAUGH FOUNDATION?**

- Yes, you must be an Australian Citizen or an Australian permanent resident to gain assistance from the Foundation.

## **HOW DO I APPLY FOR FUNDING FROM THE STEVE WAUGH FOUNDATION?**

- Check that you meet all Foundation criteria, refer to criteria list and follow ALL instructions carefully. You must complete ALL requirements of this application process.
- If you meet the Foundation's criteria please make sure you complete all sections in Part One and Part Two of the application form.
- Documents must be completed with every section filled in to be accepted. The Foundation will not accept partial or incomplete application forms.

- All invoices or quotes supplied must come directly from the supplier of the product and be valid at the time of the application and for a minimum of 3 – 6 months thereafter.
- You must ensure you provide a carefully considered and costed funding request and include everything that needs to be covered and specific to this application request. Should your application be successful, any additional or extra costs that have not been included or considered may not be covered by the Foundation.

## **WHO MAKES THE DECISION ON MY APPLICATION?**

- Every application is reviewed by the Foundation's Grants Committee. The Grants Committee works directly with a Medical Health Advisory Committee who provide advice on a case by case basis.

## **IF I DO NOT QUALIFY FOR FUNDING CAN THE FOUNDATION HELP ME GET FUNDING FROM OTHER ORGANISATIONS?**

- We review every application that we receive and like all charities we wish we could help all children/young people and their families that apply to our Foundation. There are 8,000 known rare diseases affecting up to 400,000 children/young people in Australia. Please refer to other sites and links that may be able to help you with your needs.

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# A GUIDE TO THE APPLICATION FORM

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WHEN APPLYING FOR ASSISTANCE FROM THE STEVE WAUGH FOUNDATION WHAT SHOULD I DO IF:

## **MY SITUATION IS AN EMERGENCY:**

- The Foundation is committed to doing what we can for those with rare diseases and who are in need of help. However, we are not a crisis management centre. Some cases can be reviewed independently but the Foundation does need to take time to comply with its own process and policies when approving funding. It will take up to 6 weeks from the close of applications for our committees to review and allocate funding.

## **I HAVE THE APPLICATION FORM BUT NEED HELP IN FILLING IT IN:**

- Read the instructions carefully.
- Contact your Paediatrician or Geneticist for help.
- Ask a Social Worker, friend or relative to help you.
- Make sure you have a copy of the most recent application form. From time to time the Foundation may need to review this form so it is important you download the correct and most up to date application form from the website.

## **I HAVE COMPLETED THE APPLICATION FORM AND WANT TO MAIL IT:**

- We prefer to receive your application form electronically, however we will receive mail applications if necessary. Completed applications can be sent to the offices of the Foundation. The address is clearly marked at the end of the application form.

## **THE APPLICATION FORM HAS TWO PARTS.**

1. Part One is to be filled in by a parent, guardian, family representative or parent representative.
2. Part Two is to be filled in by a Medical Professional, Geneticist or Paediatrician

WHOSE INFORMATION SHOULD YOU PUT ON THIS APPLICATION?

- The person filling in the form should clearly identify themselves in the appropriate section (Part One).
- Make sure Part Two is fully completed by a Medical Specialist, Paediatrician or Geneticist.
- Make sure you have all of the relevant information about the applicant.
- You will require an invoice directly from the supplier of the item or items we are supplying. The Foundation will be in contact with you about this.

WHAT WILL HAPPEN AFTER I SUBMIT MY APPLICATION?

- The Foundation will contact you within 10 working days of the close of applications. You will receive a letter from the Foundation that we have received your application and it is being processed.
- You may receive a request for additional information so that we can determine your eligibility and assess your application more closely to give it due consideration.
- In most cases we will process your application within 6 weeks from the closing date of applications and notify you in writing of our decision. In some cases the process may take longer.
- If your application has been unsuccessful the Foundation will notify you in writing as soon as your application has been processed.
- If your application is successful, you will be contacted by the Foundation to explain the next steps of the approved application process.

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# KEY DATES FOR THE 2010 APPLICATION PROCESS

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## WHAT IS A RARE DISEASE?

One difficulty of accurately estimating prevalence or incidence rates for rare diseases is the lack of population based epidemiological research on rare diseases. This is compounded by a general perception that rare diseases have minimal impact and are therefore considered less important and a low priority for research. Paradoxically, however, rare diseases are common. There are approximately 8000 known rare diseases, collectively affecting up to 10% of the population or over 2 million Australians including ~400,000 Australian children/young people. Rare diseases have the following common features:

- Most begin in childhood and continue throughout life
- Obtaining a definitive diagnosis is often difficult and delayed
- Many rare diseases have no cure but some can be prevented
- Neurological and intellectual disabilities occur in about half of all cases regardless of disease type and lead to loss of independence and opportunities
- Families experience isolation, psychological and financial stress
- Health professionals have inadequate access to information, education and resources
- Of deaths in children aged < 1year 35% are due to rare diseases
- Of deaths in children/young people aged between 1 and 15 years, ~10% are due to rare diseases

### Key references:

Zurynski Y, Frith K, Leonard H, Elliott E. Rare childhood diseases: how should we respond? Arch Dis Child. 2008 Dec;93(12):1071-4.

French National Plan for rare Diseases 2005-2008. Ensuring equity in the access to diagnosis, treatment and provision of care. 2004. Available from: [http://www.orpha.net/actor/EuropaNews/2006/doc/French\\_National\\_Plan.pdf](http://www.orpha.net/actor/EuropaNews/2006/doc/French_National_Plan.pdf)

Zurynski Y, Reeve K, Elliott E. International conferences on rare diseases: initiatives in commitment, patient care and connections. MJA 2007, 187(10):597 (Letter)

Schiepatti A, Henter JI, Darina E, Aperia A. Why rare diseases are an important medical and social issue. Lancet 2008; 371:2039

Zurynski YA, Peardon E, Bower C, Elliott EJ. Impacts of national surveillance for uncommon conditions in childhood. J Paed Child Health 2007; 43:724-731

## WHAT DOES THE FOUNDATION CONSIDER FUNDING?

The Foundation will consider funding the following:

- Medicines
- Treatment
- Equipment
- Items that Improve the quality of life for the applicant and their family.

## KEY DATES IN THE APPLICATION PROCESS

The Foundation will call for applications for assistance on the following three dates in 2010.

### Round 1:

**1st July 2010** (applications open) to  
**31 August 2010** (applications close)

### Round 2:

**1st October 2010** (applications open) to  
**30th November 2010** (applications close)

### Round 3:

**1st February 2011** (applications open) to  
**11th March 2011** (applications close)

Please monitor our website for the latest updates.

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# CHECKLIST

## FOR THE 2010 APPLICATION FORM

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ENSURE THAT YOU HAVE YOU COMPLETED AND ATTACHED THE FOLLOWING:

- I have checked the application form and completed all sections
- I have attached to the application form a reference from a Medical Specialist working with the applicant
- I have attached all relevant Australian Citizenship, Medicare card, Private Health Cover information and all financial information required
- I have attached all relevant tax returns and a copy of latest pay slips
- I have attached all valid quotes associated to the funding request in the application
- I have signed and submitted the application form
- I have submitted this application within the Foundation application round timeframe.

**EMAIL TO:** [INFO@STEVewaughFOUNDATION.COM.AU](mailto:INFO@STEVewaughFOUNDATION.COM.AU)

**POST TO:** STEVE WAUGH FOUNDATION GPO BOX 3331 SYDNEY NSW 2001

If you need any assistance with the completion of this form please call 1300 66 99 35

**THANK YOU YOUR APPLICATION**

STEVE WAUGH FOUNDATION AUSTRALIA.  
'SOMEWHERE TO TURN'.