

# CONFERENCE SUBSIDY

2010 CHARGE Syndrome Conference, Fremantle, Western Australia

**APPLICATION FORM** The CHARGE Syndrome Association of Australasia holds conferences on CHARGE Syndrome every two years throughout Australia and New Zealand. The Board endeavours to provide informative, worthwhile and enjoyable conferences to its members and interested families and professionals who want to keep abreast of CHARGE syndrome. The Board would like to advise that it has limited funds available to assist families (i.e. full members of the Association) to attend this year's conference. These subsidies will not cover all the expenses involved in getting you and your family to the conference, but this financial assistance may be the difference between you going and not going. We urge you to seek further financial assistance from other organisations and agencies within your local area and community (see attached document How To Obtain Financial Assistance for suggestions). Please complete this form

Family Name:	
Address:	
Telephone/Mobile:	
Email:	
Conference Attendees:	List names of all family members attending the conference (including children in childcare)
Expected Costs:	Airfares: Accommodation: Conference Registration:
Other Assistance	List here any other organisations or agencies you have applied to for funding assistance to attend this conference.

Return this form to the Treasurer, Ken Patterson, who will immediately present your request anonymously to the Board of Directors. A decision regarding your request will be made within 14 days of receipt and you will be notified shortly thereafter.

Treasurer—Ken Patterson Tel: (02) 9605 8475  
Fax: (02) 9605 8759. Email: ken.charge@hotmail.com

# How to Obtain Financial Assistance to Attend a Conference

## Financial Assistance from the CHARGE Syndrome Association of Australasia

The CHARGE Syndrome Association of Australasia holds conferences on CHARGE Syndrome every two years throughout Australia and New Zealand. The Board endeavours to provide informative, worthwhile and enjoyable conferences to its members and interested families and professionals who want to keep abreast of CHARGE syndrome.

From past conference feedback, we understand how important it is for families to attend our conferences because it is an extremely important event in their lives. For some families, it is their only opportunity to meet with others who are well versed in CHARGE syndrome and for children to meet other children.

The Board would like to advise that it has limited funds available to assist families (i.e. full members of the Association) to attend this year's conference. We understand that for some families, financial constraints make it difficult to attend conferences and to support this need the Association is offering assistance in the form of conference subsidies. These subsidies will not cover all the expenses involved in getting you and your family to the conference, but this financial assistance may be the difference between you going and not going.

To apply for the conference subsidy through the Association, please contact our Treasurer.

Treasurer—Ken Patterson Tel: (02) 9605 8475 Fax: (02) 9605 8759. Email: ken.charge@hotmail.com

We urge you to seek further financial assistance from other organisations and agencies within your local area and community and offer you this short guide on how you can obtain further financial assistance.

## Who to approach

Lions, Lionesses, Rotary, Soroptomists; Variety Club, Very Special Kids, Starlight Foundation, Ronald McDonald Charities

Local Council, Mayor or your Local Member of Parliament

A guide to government community grants throughout Australia can be found at [www.aph.gov.au/library/intguide/sp/spgrants](http://www.aph.gov.au/library/intguide/sp/spgrants)

Commonwealth Carer Respite Centre 1800 059 059 (Australia)

Centrelink (Disability Officer) 13 2717 (Australia)

Grants LINK <http://www.grantslink.gov.au> (Australia)

Our Community [www.ourcommunity.com.au](http://www.ourcommunity.com.au) (Australia)

Grant Search [www.grantsearch.com.au](http://www.grantsearch.com.au) (Australia)

Smile Foundation – Through its Family Relief Program, families around the country are provided with up to \$ 1,000 grants to meet medical expenses and other costs associated with the challenge of raising a child with a rare disease.

To meet Smile Foundation criteria;

: You must reside in Australia

: Your child be under the age of 18yrs

: Be in general hardship

: Applications or letters of support are generally made via your child's treating

Dr such as a Paediatrician or your child's social worker

For additional information please contact

Cheri Ochnio

Family Relief Program Advisor

Smile Foundation

[cochnio@smilefoundation.com.au](mailto:cochnio@smilefoundation.com.au) 0403 259 702 [www.smilefoundation.com.au](http://www.smilefoundation.com.au)

**New Zealand Specific**—Visit your local Disability Resource Centre, Internal Affairs Department or Library and access the Fundview programme. Fundview is an extensive computer program which lists all NZ funders – what they fund for and the closing dates etc. It is a free service. If you have Maori ancestry (or Aboriginal as they may have same scheme) you can approach your tribe as they all have funds available. Check out [www.fundraiseonline.co.nz](http://www.fundraiseonline.co.nz).

Try to think outside the square when it comes to your local community. Consider your school community and local church. Raise funds by holding a sausage sizzle at a large hardware chain, a neighbourhood garage sale, a trivia night or fun run. If you work in a corporate environment, hold a special day like a loud shirt / bad hair day. Approach local art groups or other special interest groups which raise funds from time to time but have no specific nominated charity. Consider approaching the local newspaper with your story. Local theatre companies sometimes allow people/groups to sell tickets for an evening performance and you get to keep the profits which could be \$600 – 700. Contact your case manager who may know of 'one off' packages of financial support being offered (or if you don't have a case manager, contact a support agency in your area and speak to their Family Services Coordinator). Speak with your child's medical specialist who may also be able to offer assistance.

You will need to find local contact details from each organisation and you will need to telephone them to confirm the best person and mailing address to send your request to.

## How to write a letter requesting financial assistance

When contacting organisations, obtain all relevant contact details (address, telephone number etc). Your letter should include the following:

The first paragraph should explain the reason why you are writing the letter

A brief explanation of CHARGE Syndrome (information can be found on our website [www.chargesyndrome.org.au](http://www.chargesyndrome.org.au))

A brief explanation of your child's diagnosis

A brief description of the conference program and describe the benefits that you and others will gain from attending. It is not only vital that you learn more about

CHARGE syndrome, but it is an important opportunity for you and your child/family to meet with other families and children with CHARGE syndrome)

A photo of your child

A complete budget of costs and an indication of an amount you are requesting from the organisation

Consider including a letter from a medical specialist who can verify your child's disabilities and your need to attend.

Finish the letter with an invitation for them to contact you, or advise that you will contact them in the next few days.

Follow up with a telephone call a week later. If you do receive financial assistance, then immediately write a letter of thanks to the organisation.

After the conference, it is important to follow up with the organisation to inform them of your conference experience and to again thank them for their contribution.

Please tell the CHARGE Syndrome Association of Australasia of your experience with requesting financial assistance. Please also indicate which organisations you have been successful and unsuccessful with so that we can improve this process for families in the future.

## Sample letter

A sample letter is attached to this document based on the above information.

This sample letter is intended to be used as a guide only and we suggest you modify it to suit your own circumstances and needs. In the event of more than one person applying to the same organisation, the request will be viewed much more favourably as an individual request rather than if it appears to be a reproduced letter.

## Further assistance

If you need more help with this process then please contact your local director (each director's contact details can be found on our website)

<http://www.chargesyndrome.org.au>. The directors are happy to help you with this process.

<http://www.chargesyndrome.org.au>

### **Obtaining Financial Assistance to Attend a Conference**

**Produced by CHARGE Syndrome Association of Australasia**

**Please note: This information and the attached sample letter are to be used as a guide only.**

This sample letter is intended as a guide only. We suggest you modify it to suit your own circumstances and needs. In the event of more than one person applying to the same organisation, the request will be viewed much more favourably as an individual request rather than if it appears to be a reproduced letter.

[Include your name,  
address,  
telephone and email address here] [Organisation's name Address Contact name]

Re: Funding assistance to attend 2010 CHARGE Syndrome Conference in Fremantle,  
Western Australia

My child has been diagnosed with CHARGE Syndrome which is a rare genetic disorder occurring roughly once in every 30,000 live births. CHARGE Syndrome is extremely complicated involving potentially life threatening heart, breathing and feeding problems along with vision, hearing, developmental and behavioural issues. The list of potential complications is extensive and further information can be found at <http://www.chargesyndrome.org.au/charge.html>.

I am currently a member of a not-for-profit organisation called the CHARGE Syndrome Association of Australasia which was formed to assist children and adults diagnosed with this rare condition. In October 2010 the Association will be holding a CHARGE conference in Fremantle, Western Australia. This is the only CHARGE conference held in this part of the world. This international conference will have well published speakers from USA and Australia presenting on topics relevant to my child including the latest information on early intervention, behavioural issues, and development all the way through to adulthood. You can read more about the conference at <http://www.chargesyndrome.org.au>. The only other major English speaking CHARGE conference is held in the USA every two years.

It would be enormously beneficial for me to attend this conference in Fremantle. The conference will cover the complicated and varied issues faced by people with CHARGE from infancy to adulthood and will also provide a rare opportunity to network with other people affected by CHARGE Syndrome to learn from their experiences. Medical and educational intervention individually tailored for each person with CHARGE Syndrome greatly assists developing their life to full potential and I would like to give my child every opportunity to do this.

Attending the conference will require travel costs, conference fees and accommodation to be paid. I expect that these will be: Travel Costs : \$ <cost> Conference Fees : \$ <cost> Accommodation : \$ <cost>

I am able to pay for the <insert an item to show that you are making an effort> but have difficulty in finding the remainder.

Your organisation has been suggested to me as one which may be able to assist by making a donation towards costs. If this is so please accept my thanks and contact me on the address above. Alternatively, if you cannot donate to individuals, a tax-deductible donation can be made to the "CHARGE Syndrome Association of Australasia" specifying that the donation to be used for <insert names> to attend the CHARGE syndrome conference in Western Australia in October 2010.

Sincerely,

[Your name]