



Leila Rose
foundation

The Leila Rose Foundation

Application for Assistance

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ASSISTANCE OFFERED BY THE LEILA ROSE FOUNDATION

Families can make an application for assistance in any or all of the following categories.



Family Support Coordinator

Shaped by our own experience, we understand how disempowering it is to learn that a child has a rare cancer, and how difficult it is to deal with the shock of the diagnosis and the complexity of the medical management. The Leila Rose Foundation can help by providing the resources of a dedicated and highly qualified family support coordinator who can assist you in navigating through the health system and outlining options to ensure that you have the best possible understanding of your child's diagnosis and treatment options.

See Guidelines for Family Support p.5



Best Doctors Review

Best Doctors are an international organisation who have a panel of medical experts who can provide a second opinion where appropriate. In reviewing your child's case they will evaluate all available medical files, tests, scans and pathology samples. They will present all review findings and recommended treatments options. Their role is to provide comfort to the family in knowing that no stone has been left unturned in sourcing the best possible treatment options available worldwide.

See Guidelines for Best Doctors Australia p.6



Financial Support

The Leila Rose Foundation assists families by funding up to \$2,500 per year, for up to 2 years.

The Leila Rose Foundation values the well-being of all family members and seeks to enable families to maintain a sense of control and dignity. The costs associated with fighting a rare childhood cancer can be insurmountable and may lead to families facing financial crisis.

See Guidelines for Financial Support p.7

ELIGIBILITY CRITERIA

Applicants who meet the following 'Guidelines for Assistance' may be eligible for assistance.

Children \leq 14 years of age at diagnosis and who:

- are a citizen or Permanent Resident of Australia, and
- have been diagnosed with a rare children's' cancer defined by that which is deemed equal or less than 5 % of childhood cancer incidence in Australia.*

**As per document "Childhood Cancer Incidence in Australia, 1983-2006" published by the Cancer Council Queensland.*

If the applicant has been diagnosed with a more common childhood cancer with a higher rate of occurrence than 5%, we regret that they will be unsuitable to receive assistance from The Leila Rose Foundation as there is often more funding, research and knowledge surrounding these cancers. We grant funding to families who have a child with a cancer so rare very little is known about it.

There may be other foundations who can provide assistance in these cases and we are happy to refer the applicants to these foundations where appropriate. Also please refer to our "Useful Links," page on our website where you can learn more about other support for children diagnosed with cancer.

The following additional documents need to be provided with Application for Assistance:

- A written confirmed diagnosis from the treating doctor is required for an application to be accepted.
- To receive assistance applicants are required to sign the patient advocate disclaimer form.

All applications for assistance are individually and carefully reviewed by our Applications Committee.

OVERVIEW OF FAMILY SUPPORT COORDINATOR ASSISTANCE

The Leila Rose Foundation offers the assistance of a highly qualified Family Support Coordinator to eligible families. The support provided by the Family Support Coordinator includes:

- Clarifying Leila Rose Foundation policies and helping the family to understand the Foundation's guidelines for support.
- Sourcing and connecting to other charities that may be able to offer assistance, not provided by, or in addition to the LRF.
- Where appropriate, accompanying the family as an objective facilitator to practitioner and/or specialist meetings.
 - Asking necessary questions, clarifying and explaining information from the oncology care team
 - Ensuring that parents have a thorough understanding of their child's health, the diagnosis and their available options.
- Sourcing additional medical or allied health support as required for the child.
- Advocacy to investigate, navigate and source any other diagnostic or treatment options that may be available within Australia or globally.

BEST DOCTORS REVIEW

Best Doctors Australia provides access to leading medical experts from Australia and around the world so that you can be confident you're making the right decisions about the medical care for your child.

Best Doctors support the Leila Rose Foundation by providing access to their services for eligible patients to be provided with diagnostic insights and a second opinion where appropriate.

Best Doctors offers:

- A review of all available medical files, tests, scans and pathology samples.
- The presentation of all review findings and recommended treatment options.

For more information on how Best Doctors is supporting the Leila Rose Foundation visit www.leilarosefoundation.org. For more information on Best Doctors Australia please visit their website www.bestdoctors.net.au.

GUIDELINES FOR FINANCIAL ASSISTANCE

The LRF will fund up to \$2500 per year for up to 2 years (\$5,000 over 2 years). The funding period begins on the date that the application is approved. Funding cannot be accumulated over two successive years, nor taken as a single lump sum. Money for accounts already paid for essential living expenses are unable to be reimbursed and we are also unable to provide cash payments for any essential living expenses. In the tragic event of a child passing, the LRF can continue to support families with meeting expenses until the next anniversary of the current application.

Essential Living Costs

Expenses will be paid directly by The Leila Rose Foundation. Applicants simply forward eligible unpaid copies of their bills prior to their due date via post or email to The Leila Rose Foundation 196a Liebig St Warrnambool Victoria 3280, or email funds@leilarosefoundation.org. Please note only eligible bills will be paid and include:

- Gas, electricity, water and council rates, home insurance, home phone, car insurance & car registration.
- Fuel vouchers will be available for families living 100km or more from their treating hospital.

Out of Pocket Medical Costs

Out of pocket medical expenses for any cancer related medical treatment (including allied health) can be claimed through the Foundation. To receive payments, patients must be registered online for their Medicare rebate. Then simply forward Medicare receipts to The Leila Rose Foundation 196a Liebig St Warrnambool Victoria 3280, or email them to funds@leilarosefoundation.org. Upon receiving the receipts, payment for the out-of-pocket expenses will be paid by direct deposit.

The Leila Rose Foundation respects and is committed to protecting the privacy of the people whose personal information it collects. The foundation is bound by The Privacy Act 1988. **The Privacy Act 1988 (Privacy Act) is an Australian law which regulates the handling of personal information about individuals. This includes the collection, use, storage and disclosure of personal information, and access to and correction of that information. The Privacy Act includes Australian Privacy Principles 2014 (APPs)**

Your personal information

LRF recognises that your privacy is very important to you and that you have a right to control your personal information. We know that providing personal information is an act of trust and we take that seriously. LRF is committed to protecting your personal information in accordance with the Australian Privacy Principles 2014. This policy governs how LRF handles your personal information and safeguards your privacy. We believe that our privacy policy not only complies with relevant laws, but also represents industry best practice.

Collecting personal information about you

LRF may collect personal information about you if you are a volunteer, when you make an enquiry, apply for or receive a service or grant, or make a donation. LRF will only collect personal information that is necessary for it to carry out its functions and services.

We will not collect personal information about you if you request us not to. However, if we are unable to collect or use your information we may not be able to engage with you effectively or at all.

Generally, we will tell you why we are collecting personal information when we collect it and how we plan to use it. The type of personal information we usually collect includes names, addresses, telephone numbers, email addresses, dates of birth and other information as listed on Grant application forms and Fundraising application forms.

Use or disclosure your personal information

LRF will only use or disclose information about you for the purposes for which it was collected, for related purposes that are likely to be expected or as otherwise permitted by the Australian Privacy Principles 2014. This may include using or disclosing your personal information if:

- The information is required or authorised by or under an Australian law or a court/tribunal order
- The health information collated is accessed by the foundation allocation committee and on acceptance provided to the LRF patient advocate.
- It will be used to confirm donations, issue receipts or to keep you informed about the foundation work.
- It is necessary to assist in managing and providing our services.
- Fundraising programs require validation.

LRF does not actively solicit donations from individuals or families to whom we have provided services or assistance. We may however occasionally seek the consent of an individual or family to whom we have provided services or assistance to use their testimony in support of our general fundraising programs.

Sensitive Information

LRF may receive and collect necessary sensitive information about an individual from relevant third parties such as hospitals, health professionals, social workers and therapists in order to effectively provide services to that individual.

LRF will not collect sensitive information about you unless you, or a parent, guardian or other person authorised to act on your behalf, have consented to our collection of such information and the collection is necessary for LRF functions or activities, or where the collection is otherwise permitted by the Australian Privacy Principles 2014. LRF regards consent as inferred when information is freely given by you to LRF, or given by family members or others authorised to act on your behalf.

LRF will only use or disclose sensitive information that it collects for the purpose for which it was collected and as otherwise permitted by the Australian Privacy Principles 2014.

Security of your personal information

LRF will endeavour to take all reasonable steps to keep secure any information that we hold about you from loss, misuse, unauthorised access or disclosure, and to keep this information accurate and up to date.

Our employees and the contractors who provide services related to our information systems are obliged to respect the confidentiality of any personal information held by LRF.

The internet is not a secure environment and although all care is taken we cannot guarantee the security of information you provide to us by any electronic means.

You should keep us informed of any changes to your personal information. Our contact details are set out below.

Access to your personal information

If you wish to request access to any personal information that LRF holds about you or seek correction of such information, please contact us via our email on mail@leilarosefoundation.org

What to do if you have a problem or question

If LRF becomes aware of any ongoing concerns or problems with data held by it, we will take these issues seriously and work to address these concerns. If you have any further queries relating to our privacy policy, or you have a problem or complaint, please contact us via our email on mail@leilarosefoundation.org

FAMILY SUPPORT COORDINATOR SCOPE - DISCLAIMER

Information provided by the Leila Rose Foundation Family Support Coordinator (FSC) is not intended to diagnose or treat any health problem or disease, or provide any indication or recommendation as to any such diagnosis or treatment. The FSC supports, but does not replace, the relationship that exists between a patient and his/her treating medical practitioner. The aim of the FSC is to empower people affected by rare childhood cancer to become well informed and to develop partnerships with health professionals who may be able to assist them to most effectively manage their child's illness. No fee is charged for the FSC service.

The Leila Rose Foundation endeavours to provide high quality advice and support with information based on peer reviewed research from reliable and reputable sources. Every effort is made to ensure that the health information provided by the Leila Rose Foundation is accurate and up to date, however, the medical knowledge of specific rare childhood cancers is continually evolving and new medical and healthcare knowledge stemming from the latest research may not always be accessible by the Leila Rose Foundation or the FSC.

By signing this disclaimer, you agree to hold the Leila Rose Foundation free from, and indemnify the Foundation against, any and all liability whatsoever with respect to:

- (a)** The reliability and accuracy of the research and information provided to you by the Leila Rose Foundation and/or the FSC; any loss or damage caused, or alleged to be caused, directly or indirectly by the Leila Rose Foundation, the FSC and / or any servants, agents, persons, company or organisations of the Leila Rose Foundation or associated with the Leila Rose Foundation; and
- (b)** Any decision made or action taken by you or by anyone else on your behalf as a result of or in connection with any information you receive from the Leila Rose Foundation, the FSC and/ or any servants, agents, persons, company or organisations of the Leila Rose Foundation or associated with the Leila Rose Foundation.

The Leila Rose Foundation does not endorse or provide any warranties or guarantees with respect to the accuracy or completeness of any information supplied by the Leila Rose Foundation, the FSC and / or any other servants, agents, persons, company or organisations of the Leila Rose Foundation or associated with the Leila Rose Foundation.

The Leila Rose Foundation takes no responsibility for any action taken, or not taken, with regard to the patient's health care. Any actions taken by the FSC will only be done so on referral to the service and with consent from the individual engaging the services of the FSC.

Each individual situation is different and individuals and families engaging the FSC should not rely on the information supplied by the Leila Rose Foundation and/or the FSC in making decisions related to any medical issues. Any material made available by the Leila Rose Foundation and/or the FSC does not constitute recommendations or advice of any nature or kind including medical advice. Medical advice should only be sought by you from qualified licensed medical practitioners.

The FSC reserves the right to refuse to provide support on behalf of an individual or family at any time where doing so would be contrary to the values, role and objectives of the FSC and/or the Leila Rose Foundation

The information supplied to you by the FSC is for general support purposes only and the Leila Rose Foundation encourages individual families to seek additional support services whilst receiving support from the Leila Rose Foundation.

The FSC and all persons, servants and agents of the FSC are not licensed or qualified medical practitioners, therefore, the information provided by them is for general informative purposes only, and does not constitute medical advice or opinion in any way.

The FSC does not diagnose or treat any illness or disease, and information provided by the FSC is in no way a substitute for the medical advice of the patient's primary care physician or other medical professional. You are always advised to talk with the patient's doctor about any health concerns that you have and about any of the information provided by the FSC. You should not rely on the information provided by the FSC.

By engaging, accessing and / or using the FSC, you hereby agree that you have read and understood the contents of this Disclaimer, had the opportunity to obtain professional advice on the terms of this Disclaimer, and that in pursuing any action or inaction as a result of any information supplied by FSC, written or otherwise is taken solely at your and the patient's own risk and liability.

EXECUTED on this _____ day of _____ 201__

Signature of Patient or Patient Guardian

Full Name of Patient or Patient Guardian

Signature of Witness

Full Name of Witness

LRF CONSENT FORM

We would like to encourage you to share your story with The Leila Rose Foundation to help us give others a better understanding of how the LRF might help families affected by rare childhood cancer. If you are happy to share some information about the journey you as a family are travelling, please discuss this with your LRF Family Support Coordinator. Filling out this form confirms that you are happy to share the information supplied by you.

I give my consent for the Leila Rose Foundation to acknowledge myself, my family and my child by name in the sharing of the information supplied by myself herein.

YES NO

I give my consent for the information supplied by myself herein to be shared by The Leila Rose Foundation via the following:

Website Newsletter Facebook Media

I give my consent for The Leila Rose Foundation to share in accordance with my consent any photographs supplied by myself herein.

I give my consent for the above freely and willingly and reserve the right that any information shared by myself herein be removed from any Leila Rose Foundation platforms at any time in the future at my request.

Signed

Date

Print Name

APPLICATION FOR ASSISTANCE

Date of Application: _____

Child's Name: _____

Child's Date of Birth: _____

Parent(s) / Guardian(s) name(s): _____

Names and Ages of Siblings: _____

Home Address: _____

Contact Information: Home Phone: _____

Mobile Phone: _____

Email Address: _____

Is your child an Australian Citizen or Permanent Resident of Australia? YES NO

What is the name, contact and address details of your child's treating oncologist?

What is the approximate distance (km) to your treating hospital? _____

Please tell us in your own words what type of support you wish to receive from the Leila Rose Foundation.

How did you hear about the Leila Rose Foundation?

Website Health Professional Word of Mouth Other *(Please specify below)*

Return this completed form to either:

Email: mail@leilarosefoundation.org Fax: 03 5561 2829

By Post: Leila Rose Foundation, C/- 196a Liebig St, Warrnambool 3280

CHECKLIST FOR APPLICATION

- I have read and understand the areas of assistance provided by the LRF
- I have read and understand the guidelines for assistance offered by the LRF
- I have read and understand the LRF Privacy Policy
- I have read and signed the LRF Patient Advocate Disclaimer
- I have read and signed the consent form
- I have included a Letter from our treating Specialist confirming diagnosis.
- I have completed all questions within the application for assistance.