



Batten Disease Clinical Trial Resources for Families

1. 'How to search for clinical trials' – Video Tutorial

This short tutorial (approx. 3min 30s) provides an easy step-by-step guide to accessing and searching the global database 'clinicaltrials.gov' for information on studies that are *currently* open and recruiting patients, and those that will *soon be* open and recruiting.

Presented by Dr Ineka Whiteman, Head of Medical & Scientific Affairs and Head of Research at BDSRA Australia. [Watch the video](#) on our website.

2. Understanding Clinical Trials

The clinicaltrials.gov site provides a useful resource [Learn About Clinical Studies](#) explaining the clinical trial process, terms and definitions.

See also the American Society of Gene and Cell Therapy:

Stimulating research (see the story "A Mother's Journey" with Sharon King of Taylor's Tale)
<http://patienteducation.asgct.org/patient-journey/stimulating-research>

Understanding a Clinical Trial

<http://patienteducation.asgct.org/patient-journey/considering-a-clinical-trial>

Clinical Trial Process

<http://patienteducation.asgct.org/clinical-trials/clinical-trials-process>

Gene Therapy 101

<http://patienteducation.asgct.org/gene-therapy-101>

Batten Disease Gene Therapy

<http://patienteducation.asgct.org/disease-treatments/batten>

3. Staying Up-To-Date on Clinical Trial News

BDSRA Australia communications

A great way to keep in touch with study updates is by following our [Facebook page](#), visiting our [website](#) and/or via our mailing list. Please email info@bdsraaustralia.org if you wish to be added to our mailing list or to update your details.

Batten Disease News

Subscribe to these weekly email alerts at <https://battendiseasenews.com>

4. Connecting with Other Families

Within the BDSRA Australia community, there have been a small number of families who have participated in clinical trials abroad. They are happy to share their insights, practical knowledge and experiences with those who might be considering pursuing potential involvement in trials overseas. Please contact BDSRA Australia at info@bdsraaustralia.org if you would like to be put in touch.