

## For Parents of newly diagnosed children:

As a parent of a child newly diagnosed with Cystinosis you will read a lot in the weeks and months ahead on this and other websites as you seek answers to your many questions.

You may find some of what you read upsetting as you learn more about Cystinosis and how it has affected peoples lives. However, it is important to note that there is a very wide range of out-comes for people with Cystinosis, and the ongoing improvements in the treatment of the condition means that children with Cystinosis are experiencing much better outcomes and many are living happy and active lives.

You and your child face many challenges ahead, but it is still possible that you can still fulfil all your dreams for your child.

We hope that you will find our website useful and informative, and when you feel that you would like to discuss what life is like living with Cystinosis, its treatment and any other questions you may have, our Foundation members will be happy to talk with you. If you email us your contact details, someone will get back to you as soon as possible.