CYSTIC FIBROSIS / LA FIBROSE KYSTIQUE

Kaitlin Atkinson Family Resource Library / Bibliothèque de ressources familiales Kaitlin Atkinson

Resource List / Ressources

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Alexandra Deford, a precious and precocious girl, was just eight years old when she died in 1980 following a battle against cystic fibrosis. Her poignant and uplifting story touched the hearts of millions when it was first published and then made into a memorable television movie. A new introduction contains information on the latest cystic fibrosis research, and a touching postscript reveals how the Deford family came to terms with the loss of Alex.  
FAM RJ 456.C9 D43 1997

This book offers sensible advice on dealing with CF clinic staff, coping with school physiotherapy, and discussing CF with friends and family. In response to concerns voiced by adolescents with CF, this revised edition tackles issues such as sexuality and personal relationships unique to people with CF. Also included is a section dealing with the transition to adult CF clinic care.  

Comprendre la fibrose kystique: un guide d'enseignement -- Markham, ON: Solvay Pharma
FAM RJ 456.C9 U514

Explores the history, symptoms, diagnosis, and treatment of cystic fibrosis, reviews ongoing research, and discusses how to live with the incurable genetic disease that is often called "65 Roses".  
FAM RJ 456.C9 A274 2003

This book is based on interviews with people living with CF and their family members, which covers all aspects of the disease such as the day-to-day dealings with the illness, diagnoses procedures, daily therapies, and stories of CF patients now in their 30's and 40's.  
FAM RJ 456.C9 A74 2006

This picture book tells the story of one day in the life of a little girl fighting Cystic Fibrosis. It was written in order to help these small but mighty few find a sense of commonality and see fun photos of other kids who are just like themselves.  
FAM RJ 456.C9 L79 2005

Introduces readers to the disease of cystic fibrosis, its causes, how it affects the body, and what it's like to live with the disease.  
FAM RJ 456.C9 G73 2002

Mallory's 65 roses / Smith, Diane Shader -- 1997.  
This is an engaging story of Mallory, a creative and energetic little girl afflicted with cystic fibrosis (CF), an inherited lung disease. She explains her condition and its ramifications in her own words, painting a picture accessible to children and poignant to adults.  
FAM RJ 456.C9 S64

Miguel explains what he has learned about Cystic Fibrosis from his friend Sarah, who has the disease.
FAM RJ 456 .C9 D68

This reference manual shows parents where and how to look for information covering virtually all topics related to cystic fibrosis.
FAM RJ 456 .C9 O3 2004

Offers parents of children with chronic health issues practical strategies and suggestions to help them cope with their child's condition and the constant physical and emotional challenges they face.

Designed to help kids better understand their classmates with cystic fibrosis, this brightly illustrated picture book also educates families, teachers, school nurses, parents, and caregivers. Appropriate for ages: 5-10 years.
FAM RJ 456 .C9 H46

*Understanding Cystic Fibrosis charts the progress that has been made in identifying the mutations that cause CF and in understanding how these genetic errors cause a disease whose symptoms can range from mild respiratory distress to life-threatening lung infections.*

**Web Sites / Sites internet**

Cystic Fibrosis (CF) – About Kids Health / Fibrose Kystique (mucoviscidose)  

Cystic Fibrosis Canada / Fibrose kystique Canada  

Fibrose kystique Québec / Cystic Fibrosis Quebec  
http://www.fibrosekystiquequebec.com/fr/

Cystic Fibrosis – MedlinePlus from the US National Library of Medicine  

What is Cystic Fibrosis? NIH - National Heart, Lung and Blood Institute  
http://www.nhlbi.nih.gov/health/topics/topics/cf/

Kids Health - Information for Parents, Teens and Kids from the Nemours Foundation  
www.kidshealth.org

Cystic Fibrosis Foundation
Cystic Fibrosis and Your Baby – March of Dimes

Cystic Fibrosis Parent Handbook – Seattle’s Children’s Hospital

**Apps**

CF MedCare
- M-Data SA
- English, German, Dutch, French and Italian / anglais, allemand, néerlandais, français et italien
- Free / gratuit
- Last updated Jan 2017 / Mis-à-jour 2017 janvier
- Many CF patients have a complex and time consuming regimen, which can lead to non-compliance. While the reasons for non-compliance are complex, simple forgetfulness has been cited as the most common cause for missed treatment. Offered as a supportive tool, CF MedCare: Allows users to create their own treatment profile (or multiple profiles for family members and care takers) adding all their medications, schedules and instructions; Alerts; Captures the user’s compliance; Provides the ability to share the data; Reminds users when it’s time to renew their medication(s); Creates monthly compliance records. / Beaucoup de patients atteints de mucoviscidose ont un régime complexe et chronophage, qui peut conduire à la non-conformité. Bien que les raisons de la non-conformité soient complexes, simple oubli a été cité comme la cause la plus commune pour le traitement manquer. Proposé comme un outil de soutien, MedCare CF: Permet aux utilisateurs de créer leur propre profil de traitement (ou plusieurs profils pour les membres de la famille et des preneurs de soins) en ajoutant tous leurs médicaments, les horaires et les instructions; Alertes; Capture le respect des utilisateurs; Offre la possibilité de partager les données; Rappelle aux utilisateurs quand il est temps de renouveler leurs médicaments (s); Crée les dossiers de conformité. L’application MedCare CF envoie des rappels pour prendre le bon médicament, au bon moment, avec les instructions qui ont été saisies (i.e. Prenez avec le dîner), même si l’utilisateur est déconnecté.
- Available from / Disponible depuis iTunes & Google Play

**Local Contacts / Liaison régionales**

Cystic Fibrosis Clinic - CHEO / Clinique de fibrose kystique – CHEO
401 Smyth Road
Ottawa, ON K1H 8L1
Fax: 613-738-4865
Nurse Coordinator: 613-737-7600 ext. 2214
Physician referral is required with confirmed diagnosis of cystic fibrosis / Une demande de service par un médecin est nécessaire avec un diagnostic confirmé de fibrose kystique.

Cystic Fibrosis Canada
Regional Office
308 Palladium Drive, Suite 106
Kanata, ON K2V 1A1
613-482-7912
http://www.cfottawa.ca/
This guide provides medical material for information purposes only and is not intended to replace the advice of your physician. The information may not always apply to your individual situation.

The guide represents material available in the Family Resource Library collection at CHEO. It is not intended to be an exhaustive list. Your local public library may also be able to provide you with information.

If you require materials in alternative formats, please contact the library at 613-737-7600 ext. 2157 or at library@cheo.on.ca.