



SICKLE CELL FOUNDATION OF ALBERTA

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The Sickle Cell Foundation of Alberta Annual Report - 2004

In 2004, our volunteers have achieved great things - here are just a few of them:

We have handled approximately 50 enquiries by phone, letter, and increasingly by e-mail. Most of our enquiries were from first-time callers, and many of them have kept in contact.

We have launched our online support group (discussion group) where people share their fears and experiences. Any interested party can contribute to the online support group. The online support group is monitored daily by the Foundation president and any inappropriate comments are removed.

We organized a seminar at the University of Alberta on August 11 2004, which was attended by about 30 doctors and medical students. The speaker was Dr. Sudam L. Kate, a retired professor of genetics from B.J. Medical College in Pune, India. He gave a lecture on "The Study of Sickle Cell Anemia amongst Tribal Population Groups from the State of Maharashtra, India." The event was successful and gave insight into the different approaches that are used in treatment and prevention of sickle cell disease globally.

Our campaign to get Alberta Blue Cross to subsidize hydroxyurea was successful. Authorization to subsidize hydroxurea means that individuals with sickle cell disease can apply for Alberta Non-Group Blue Cross to receive 70% coverage for the cost of hydroxyurea. The remaining 30% of the cost of the drug will be paid by the individual (up to a maximum of \$25 per each three month prescription).

We achieved modest success in our 2004 fundraising campaign. We raised \$1000.00. These funds are available to further research into the treatment and prevention of sickle cell disease. Some of the funds can also be used to help cover premiums and costs of obtaining Alberta Non-Group Blue Cross and hydroxyurea for those experiencing financial hardship.

We have submitted an application to the Canada Customs and Revenue Agency to become a nationally recognized registered charity. When successful, the registration will allow us to issue official receipts to our donors, which will reduce their taxable income. Once our organization is registered, we will also be exempt from paying income tax (under Part I of the *Income Tax Act*).

Finally, the Sickle Cell Foundation of Alberta has been listed by the Canadian Directory of Genetic Support Groups.

I think you will agree that this is an impressive list of achievements for the foundation. We need to reach more sickle cell patients and to reach them earlier in their diagnosis so we can support them. During the next year we would like to accomplish the following:

We would like to start and maintain a newsletter to be mailed out four times a year. We would like the newsletter to be our main way of communicating with our members and volunteers.

We would like to continue with our fundraising drive and find more innovative ways to raise money.

We would like to increase the foundation profile (through radio, TV, newspaper) in the hope that this will increase membership and help in our fundraising efforts. We would also like to increase participation in our online support group.

So how are we going to achieve our vision? It all comes down to resources, both human and financial. We have an outstanding team of volunteers on our board, but we have to increase our funding if we are to reach more patients.

Ekua Yorke