



INTERNATIONAL GROUPS REPORT

**DebRA de Costa Rica
July-2003---February 2004**

Fundraising

Since this is the first time we present a report as DebRA de Costa Rica, I will tell a little bit of history about us.

We started working in the year 2000 with a different name, Fundación Marvin Barquero Chavarría, because of a little boy affected by ichthyosis (Netherthon Syndrome)

We grew during the first two years, had a very succesfull fundraiser in 2001 for such a small country (\$200.000.00), and after having been in contact with DEBRA UK, DEBRA USA, DEBRA CHILE, DEBRA MEXICO and A.E.B.E. in Spain, decided to start a new foundation, with the name of DebRA de Costa Rica.

Since this is such a small country, and there are only 37 known cases of E.B., we also work with children with ichthyosis (15 known cases) and about 75 children with severe Atopic Dermatitis.

In the last two years we have also helped children with vascular malformations (300 cases), and bought a laser equipment to contribute with their treatment.

So, our first active year as DEBRA has been 2003.

During 2003 we have had small fundraising events such as a bingo, a gala dinner, second hand clothes sales, a soccer match between veterans world-cup players from San Salvador and Costa Rica, several classical concerts, small loteries etc, and also income from the laser treatments for a total of \$140.000.00\

(one hundred and forty thousand dollars).

We also were able to receive a donation in January 2004 with the help of DebRA USA from an american family.

Special projects

a)From the very beginning, together with DEBRA Chile, we have been dreaming of forming a DEBRA in Spanish for the Latin American countries.

We hope to be able to formalize this dream in 2004, we are planning to use some of our January donation for that purpose, and are working with Debra Chile, Mexico, and hopefully Spain to set a date for this project.

b) We will have a soccer match between the Master Team from Holland and the Master Team from Costa Rica on the 17 of July, and hope to be able to raise around \$50.000.00

It seems to be that in most countries, the Master Teams play for benefits.

It would be very interesting for DEBRA in each country to contact their master team, and have a match between two DEBRA countries, and have this become a worldwide activity, not only for fundraising, but to have more people become aware of the disease.

c) We have a project for fundraising with a supermarket chain for August, September and October and a concert in October, which should yield another \$75.000.00, we do not have a formal confirmation for the concert yet.

Conferences and meetings

Dr. Eugenia Cuesta (Debra Dr) have attended seminars for Laser Safety in Phoenix, Arizona (november 2003), a birthmark workshop in Brazil (october 2003), and together with our dermatologist, Dr. Mario Sancho Torres assisted to the Pediatric Dermatology Conference in Washington in January 2004.

We have sent an invitation, but do not have a confirmed date , for a visit from Dolores Cogliano and Madeline Weiner from DEBRA USA, which we hope to coordinate with a visit from Dr. Lawrence Schachner in the next couple of months.

Research and medical news.

We have not been able to do any research yet, we hope to be able to start working together with Debra Chile on that in 2004 or 2005, since they have offered us their help.

Our DEBRA Doctor, Eugenia Cuesta, receives a salary from DEBRA C.R, but works together with the Pediatric Dermatologist in the Children's Hospital, Dr. Mario Sancho so all the children that are beneficiaries of our foundation receive all the benefits the National Healthcare System (Caja Costarricense de Seguro Social) can offer them, plus the complementary services that they receive from DEBRA C.R., such as a doctor on call 24 hours, and medicines and treatments not provided by the system.

We have sponsored a national registry of EB patients by a last year medical student, and consider it a plus that EB babies are referred to the Dermatology Department of the Children's Hospital immediately after birth, as a matter of fact, we had a birth last week that seems to be EBS.

We would like to be able to send specialists in the different areas, such as dermatologist, dentist, psicologist, physiotherapist, microbiologist etc, to learn to deal with and to teach the families to live with EB, to centers where they can receive more education on EB.