



## The Italian Catholic Federation and the Cooley's Anemia Program at Children's Hospital

Dear Brothers and Sisters of the ICF,

The main charity supported by the ICF is the Thalassemia/Cooley's Anemia Program at Children's Hospital Research Center, Oakland. Since 1994, the ICF has donated \$925,000 for this cause.

For more information, please contact:

Teresa Helfand  
Chairperson,  
Apostolic Committee

## A Letter from Laurice Levine, Thalassemia Outreach Coordinator

Dear ICF Members:

As your National Charity, the Thalassemia/Cooley's Anemia Staff and most especially all of the patients and families in our care, have benefited greatly from your years of support and generosity. We think that it is vital for you to know how we spend the money that you donate to us each year. The spreadsheet on the last page was developed to track the annual monetary donations given to us by the ICF. The descriptions of each category are below. If you have questions, please contact Laurice Levine, Thalassemia Outreach Coordinator, at 510-428-3885 x 5427 or [LLevine@mail.cho.org](mailto:LLevine@mail.cho.org). Again, thank you for making our work possible and improving the quality of life for people with Thalassemia.



*Entrance to Children's Hospital Oakland Research Institute: The building once housed University High School and has been restored.*

## Research & SQUID:

Approximately one half of donated ICF funds go towards medical research studies, which improve the quality of life of patients, as well as searching for a cure; and the running and maintenance of the SQUID machine. The SQUID measures stored liver iron, which occurs as a result of routine blood transfusions, using safe, non-invasive technology, therefore eliminating the need for a surgical procedure. Please see the attached research update to learn about our current studies. If you would like a copy of the "2010 Research Update", please contact Laurice Levine.



*A research laboratory at Children's Hospital of Oakland Research Institute*

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### Patient Events:

An integral part of our Thalassemia outreach program is patient services. We plan events for patients and families that offer diversion, psychosocial support, peer support and mentoring, and strengthen the ties between staff and patients. Events include, but are not limited to the following:

**Christmas Party:** We fund our annual Christmas party partially through the ICF donation. This special event has grown from 70 to 350 guests over the last decade. In 2000 the cost was approximately \$2,900 and in 2009 the party cost \$11,700. Along with funds ICF branches run toys drives,

providing more than half of the gifts given to patients and siblings. An ICF member also plays Santa Claus and/or Mrs. Claus or an Elf for the party.

**Patient Retreat:** Approximately 25 young adult and adult patients gather for a weekend away (former locations include Santa Cruz, Monterey, Lake Tahoe, Healdsburg) for psychosocial work, therapeutic activities, peer support, and diversion.

Also included are Patient Dinners, Bowling Nights, Picnics, Teen Outings, Family Education Nights, Conferences, and Children's Programs.

  
**Patient Sponsorship:**

ICF funds are also used in assisting patients and families from around the country and sometimes the world to visit our Thalassemia specialty center for a comprehensive medical and psychosocial consult, which is recommended to be done at least once a year. Our Thalassemia doctors will then collaborate with the patient's primary doctor to assure that they receive optimum care throughout the year. Financial sponsorship may include airfare, various forms of public transportation, and accommodations.

We also sponsor patients to attend national conferences put on by Cooley's Anemia Foundation/Thalassemia Action Group, the Thalassemia Support Foundation, as well as our own at Children's Oakland. This is a time where patients are given the opportunity to learn about the disease and gain a therapeutic experience by meeting others going through the same challenges.

**Education and Outreach:**


We provide education and outreach on Thalassemia to the hospital community and in the greater community. With regards to the ICF education and outreach includes the annual conventions, branch visits, and fundraisers. ICF funds enable us to participate in health fairs throughout the community; offer in services to medical professionals; and create and disseminate the "Perspectives" Thalassemia newsletter and other literature.

**Patient Medical Expenses:**

ICF donations make it possible for us to financially assist patients and families who are unable to pay for medical services, treatments and medications. We do not turn any patient away. We also help with funeral arrangements when needed.

**Special Projects:**

ICF funds have sponsored special projects such as our "Live to Give." A CD explaining this program is available through Laurice Levine.



**Three Months as a Thalassemia Patient**  
**Excerpted from Laurice Levine's 2010 Speech at the ICF Annual Convention**  
**(See 2010 Convention Highlights for full speech.)**

- **Hematology – everything blood related:**  
6 blood TX – 12 units of blood – 43 hours  
Blood Tests which include my pre-tx type and cross match and Shots – 1.5 hrs  
Doc appt with my Hem – 30 minutes  
**45 hours**
- **Chelation therapy which is something I do to get rid of excess iron which results from blood transfusions:**  
**1590** Hours of wearing the Desferal Pump  
**12** hours mixing Desferal and organizing supplies
- **Cardiology** – heart failure is the #1 cause of death and I have a complex cardiac history including 2 incidences of congestive heart failure, a dx of pulmonary hypertension since resolved and a cardiac clot.  
Echocardiogram, 2 EKGs, 2 Cardiology appts. – **3 hours**
- **Gastroenterology:**  
Follow-up Doctor appointments: **2 hours**. I had 3 endoscopy in 9 months – Pyloricstenosis
- **Dermatology:**  
2 Dermatology appointments – r/o melanoma; wound care biopsy and 6 stitches; follow up – **4 hours**
- **Research Studies:**  
- Osteoporosis - 1 week wearing an Actigraph 24 hrs a day to monitor joint movements  
I have the bone age of a 71-year-old woman – riddled with Osteopenia, close to osteoporosis. Arthritis is in my back, hips and other joints.  
20 minutes a day standing on a vibrating platform – **28 hours**  
- Trip to LA – Oral Glucose Tolerance Test to check for diabetes and MRI study of iron storage in the pituitary gland, pancreas and heart – **9 hours**  
**= 37 hours**
- **Alternative Medicine – immune system – infection is the second leading cause of death among people with Thalassemia,**  
Acupuncture – **5 hours**
- **Pain Management:**  
Chiropractic – 12 visits adjustments, traction, muscle therapy– **4 hours**  
X-Rays – back and hand – **30 minutes**  
Physical Therapy – visits to the therapist and home exercises - **17 hours**  
Pain Doctor – **30 minutes**  
**= 22 hours**
- **General Care:**  
Appt with primary care – annual physical – **1 hour**  
16 medications = 30 pills a day – organizing meds every Sunday – **3 hours**  
Traveling to medical appointments – **39 hours**  
Paperwork, paying bills, making appointments, phone calls etc – **10 hours**  
**=53 hours**

**Grand Total 183 hours (61 hours a month) + 1590 Hours of wearing the Desferal Pump**

Sept 1994-present

ICF Expenditures

Prepared by LLevine  
Updated November 7, 2010

Year	Amount	Research & SQUID	Patient Events	Patient Sponsorship	Educ/Outreach	Pt Medical Exp.
Sept. 2010	\$58,000	Not spent	\$3,000	\$4,000	not spent	not spent
Sept. 2009	\$62,000	\$43,000	\$4,000	\$4,000	\$5,000	\$6,000
Sept. 2008	\$57,000	\$37,000	\$9,000	\$5,000	\$1,200	\$4,800
Sept. 2007	\$54,000	\$35,000	\$10,000	\$4,500	\$500	\$4,000
Sept. 2006	\$52,000	\$30,000	\$8,000	\$6,500	\$1,500	\$4,000
Sept. 2005	\$113,154	\$65,000	\$10,154	\$15,000	\$8,000	\$15,000
Sept. 2004	\$45,000	\$23,000	\$3,000	\$3,500	\$3,500	\$12,000
Sept. 2003	\$51,000	\$25,000	\$2,000	\$6,000	\$5,000	\$8,000
Sept. 2002	\$56,000	\$52,000	\$4,000	-----	-----	-----
Sept. 2001	\$49,000	\$27,500	\$5,500	\$7,000	\$2,000	\$7,000
Sept. 2000	\$52,000	\$32,000	\$8,000	\$6,500	\$1,500	\$4,000
Sept. 1999	\$53,000	\$35,000	\$4,000	\$5,500	\$2,000	\$6,500
Sept. 1998	\$58,000	\$39,000	\$6,000	\$3,500	\$1,500	\$8,000
Sept. 1997	\$53,000	\$35,000	\$5,000	\$4,000	\$5,500	\$3,500
Sept. 1996	\$50,000	\$33,000	\$5,000	\$4,500	\$1,500	\$6,000
Sept. 1995	\$50,000	\$33,000	\$5,000	\$4,500	\$1,500	\$6,000
Sept. 1994	\$11,600	\$11,600	\$0	-----	-----	-----
<b>GR. TOTAL</b>	<b>\$924,754</b>	<b>\$556,100</b>	<b>\$91,654</b>	<b>\$84,000</b>	<b>\$40,200</b>	<b>\$94,800</b>
1982-1993	Donations went	to Dr. Hyman in LA.				

ICF Apostolic Committee  
Teresa Helfand  
(Chairperson)  
Rev. Msgr. Daniel Cardelli  
James Acitelli  
Marco Galeazzi  
Vincent Picciola



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