

Press Kit 2007

What is The Andre River of Life Foundation?

A child is diagnosed with a terminal disease. The mother finds herself alone. Why? Statistics shows that 78% (8 out of 10) couples separate or divorce once it is determined that their child suffers a life-threatening or catastrophic chronic illness. Invariably, mothers become the single care-givers. The struggles of these lone parents and their dying children remain hidden to the world. So do the impossible choices that these mothers must make. If a mother quits her job to care of her child, the family finances shatter. If she chooses to continue to work, then her dying child must often face suffering and treatments alone, a frightening prospect for both mother and child.

The Critical Role of the Andre Sobel River of Life Foundation

Working with select hospitals nationally, the Foundation provides crisis funding when NO other help is available. Payments go directly to landlords, utility companies, grocery stores, insurers. The hallmark of the ASRL program is to help within 24 hours. The parameters of assistance are as wide as are the needs of the families. The Foundation helps to enhance their lives as well as to salvage them from crisis. Grants have been made to buy wigs for the self-conscious teenager losing her hair to chemotherapy, comfortable beddings, and music lessons for a sibling feeling the neglect of a mother overwhelmed with the needs of the critically ill child. In other cases, grants have covered travel cost to bring relatives in to help or, to pay for a last vacation for mother and child.

The speed and simplicity of the process make this foundation unique. The caregiver does not fill out any forms. Instead, the hospital social workers identify the financial crisis and apply to the Foundation using an electronic form. Founder Valerie Sobel is keenly aware that such monies do not replace the health or the life of the child. She intends only for the

work of ASRLF to soften the crisis and to increase the families' ability to cope. Her objective remains focused and pragmatic - that relief should come promptly.

The Inspiration for the Andre Sobel River of Life Foundation

Ms. Sobel's inspiration for the Andre Sobel River of Life Foundation stems from her own staggering loss - that of her teenage son Andre who died of a malignant brain tumor. Within the same year, her husband took his own life. Over the subsequent months of grief, she sought a way to honor their lives. As she reflected, Ms. Sobel realized that through her ordeal, she had never needed to worry about finances or the lack of any other resource. She had been able to help Andre in every imaginable way. She wondered how she would have managed had financial and emotional support been lacking. Then the question hit her - what might be the plight of mothers without her resources? How could they possibly cope? Ms. Sobel says she experienced an unexpected upwelling of gratitude for her blessings and also a burst of clarity as to what the mission of the Andre Sobel River of Life Foundation must be.

Exploring the world of the single care-giver Ms. Sobel found a place of quiet suffering where mothers staggered from crisis to crisis. They had few advocates. In one case, the request for help was to provide a part time caregiver while the mother went to work. The cost of this would have been \$2200. Ms. Sobel asked a mother how much money would allow her to give up work to care fulltime for her terminally ill son. The answer: \$800 per month. "Just imagine the senselessness of forcing that mother to leave her dying child and go to work, so she can pay a stranger to do what she most wants to do" reasons Ms. Sobel.

It is Valerie Sobel's intimate understanding of the stress upon these families that explains the diversity of expenses covered by the ASRLF Foundation. From shelter and food to transportation for chemotherapy or alternative therapies, to ballet lessons for a patient's sibling, and burial

costs. Observes Ms. Sobel, "our society is only as humane as its treatment of those so diminished by crisis that they cannot speak for themselves." Her work has helped every kind of family, but nearly 70% of households are those where the mother is the sole parent. In its first six years, the Andre Sobel River of Life Foundation has assisted thousands of families as they struggle with life and death. It projects that by the end of 2006, the total number of recipients will approach 6,000.

At A Glance

Mission Statement:

"The Andre Sobel River of Life Foundation enables single parents of children with life-threatening illnesses to care for their children fulltime by relieving financial burdens when other resources are exhausted or unavailable. "

ASRL vision statement:

"By caring for the care-giver, we care for the child."

Currently in their sixth year of operation, the Foundation has launched a major expansion, and their program now operates at a network of pediatric hospitals coast-to-coast.

Letters from Mothers

A mother struggles with two teens, one of whom has had a heart transplant and a difficult road ahead. She writes:

"There are so many things to worry about, but you have relieved me of one of the biggest and allowed me to instead focus on the most important, and that is my girls. Without the worry of 'are we going to have a home,' I can focus on A...'s recovery and also on the needs of my other daughter S. and us as a family...I have always taken care of us, and now when I needed to most, I was at a loss and you took care of us. Thank you from the bottom of our hearts."

This mother of a 13-year-old agonized with her daughter over the nerve damage to one side of the child's face, part of the impact of a brain tumor. The Andre Sobel River of Life Foundation paid for a corrective surgery that

also saved her eyesight:

She writes "...just knowing that she may regain movement in her face has given my R... such hope. She has made an effort to make new friends and is socializing more. She is even talking about going to her senior prom! I know that if she had not had the surgery, she would never have dreamt of such a thing! You truly have given her hope and a dream."

Case Histories: The Andre Sobel River of Life Foundation at Work

The P family is composed of a single mother and five children in their late teens and early 20s. The father has abandoned the family and does not contribute any financial support. All three sons have hemophilia and are developmentally delayed, as is one of the daughters. The mother has what is medically known as a "fragile X syndrome," the cause in part of her children's medical problems.

The oldest son cannot be cared for at home and lives in a facility. Mom financially provides for his personal requirements. All of the other children are dependent on their mother for shelter, care, and their basic life needs. The family barely scrapes by on assistance received from government agencies.

A few days before Christmas 2005, their rental house burned to the ground in what is assumed to be a fire started by their Christmas tree. All but one child were able to escape the flames. Trapped inside were one son and the mother, who refused to leave him. The teen was too large for her to carry him. Ultimately, she managed to push him through a window and jump down after him. Because of the boy's hemophilia, his mother had taken a grave risk that he would suffer massive internal bleeding that would kill him. Luckily, the paramedics on scene rushed him to the hospital where he made a full recovery within a few days.

This tragic family - already living in hardship - was left at Christmastime with no home, no personal possessions, and none of the gifts that had been donated by the hospital treating the children. ASRLF provided rent money for the first and last months rent in a new apartment, along with grocery, gasoline and Target and phone cards. In addition, the Foundation arranged for a special bed for the teen injured in the fall.

Case: N.... is a 17-year-old diagnosed 2 years ago with leukemia. Mom is single with one other child, and N.'s father is not paying child support. N...'s treatment is complicated necessitating experimental treatments. The mother was also recently diagnosed with cancer and is unable to work. The family is experiencing great emotional and financial stress.

ASRL Grants to date: \$2,056 housing, \$185 utilities, \$319 car insurance, \$200 groceries, \$280 for household expenses.

Case: D... is a 3-year-old with Williams Syndrome, a neurobehavioral congenital disorder that affects development. Mom is single and has two other children, including a newborn. She sold her house in order to buy a reliable car to get D... to doctor visits, but the insurance lapsed 24 hours before mom had an accident that totaled the car.

ASRL Grant: \$850 car repair, \$1204 for 2 mo. housing, \$60 utilities.

Case: P... is a 5-year-old with a Stage IV tumor primarily in the left kidney. Her prognosis is very guarded. Mom is single and cannot work in order to care for her daughter. P's 6th birthday is next weekend and mom has no money to make a party or buy gifts.

ASRL Grants: \$300 groceries, \$250 Target card, \$200 household expenses, \$500 housing.

The Andre Sobel River of Life Foundation: Hospital Network

In 2005-06, the Foundation launched a campaign to further expand the network of pediatric hospitals where their program operates; from Los Angeles to Boston.

Children's Hospital Boston

Boston, MA 02115

www.childrenshospital.org

Children's Hospital Los Angeles

Los Angeles, CA 90027

www.chla.org

Children's Hospital Medical Center of Akron

Akron, OH 44308-1062

www.akronchildrens.org

Children's Hospital of Pittsburgh

Pittsburgh, PA 15213-2583

www.chp.edu

City of Hope

Duarte, CA 91010

www.cityofhope.org

Institute for Families

Los Angeles, CA 90027

www.chla.org

Jonathan Jaques Children's Cancer Center

Miller Children's Hospital

Long Beach Memorial Medical Center

Long Beach, CA 90801
www.memorialcare.org

Lucille Packard Children's Hospital at Stanford
Palo Alto, CA 94304
www.lpch.org/

Mattel Children's Hospital at UCLA
Los Angeles, CA 90095
www.pediatrics.medsch.ucla.edu

Texas Children's Hospital
Houston, TX 77030
www.texaschildrenshospital.org

The Children's Inn at the National Institutes of Health
Bethesda, MD 20814-1509
www.childrensinn.org

Children's Hospital of Philadelphia
Philadelphia, PA 19104-4399
www.chop.edu

For a look at a hospital's perspective, this review is from the Mattel
Children's Hospital at UCLA:

"Since last January when we began this partnership with you, your foundation has assisted twenty of our families in crisis. You have helped with rent and mortgage payments, food, utilities, gasoline, and gift certificates. This has meant that some families have been able to maintain stable and safe homes for their sick children. Others have been able to ensure transportation to medical appointments to receive care. For some families, the assistance has allowed the parent to enrich the child's life while receiving treatment. Your help has even allowed a terminally ill child to

be in her own home with the level of care necessary for her comfort. These funds have given families time to regroup and focus on the needs of the child. Your foundation is unique in that it is the only agency with the capacity to respond emergently without the reams of paperwork required by other agencies. This often means the parent does not have to leave the bedside and can focus on caring for the child." -- Dr. Sakamoto and Staff

Testimonials to the Andre Sobel River of Life Foundation

California First Lady Maria Shriver:

"Thank you so much for all your efforts to help the Chavez family coordinate the burial of their beloved daughter Paulina. I understand you were an integral part of the behind the scenes work to secure funding for the family during their time of need. Please know what an incredible difference you made and I am so grateful."

I still would like to see the rest of her letter saying: "Thank you for the outstanding community work and service to our great state - you are truly an inspiration for all Californians"

Ernest Katz, PhD

Children's Center for Cancer & Blood Diseases, CHLA

*Professor of Clinical Pediatrics and Psychology, KECK-School for Medicine,
USC:*

"As Director of Behavioral Sciences in one of the largest pediatric centers (CHLA), I am very familiar with the tremendous difficulties faced by single parents coping with the serious illness of one of their children. They are often pressed beyond the breaking point, and I am unaware of any resource other than the Andre Sobel River of Life Foundation that targets this at-risk population, offering immediate and direct assistance in desperate situations. This support is often the difference between a mother's ability to cope and keep her family intact or get her sick child the life-saving medical care."

Paul Koretz

California Assemblyman, 42nd District:

"I am extremely impressed with the amazing job that you and your staff have done in launching the Andre Sobel River of Life Foundation in memory of your beloved son. It is clear that your efforts have already had an immediate impact upon many families at risk during some of their darkest days. It is sad to think of the alternative if they did not have your foundation to lean on...I stand ready to do whatever is within my power to support your efforts."

Rep. Ellen Tauscher

California 10th Congressional District:

"Being a single parent today is hard enough, but being a single parent of a child with a life-threatening illness is both mentally and financially hard-hitting. This is why the work of the Andre Sobel River of Life Foundation is so important. By relieving the financial burdens of the parent, the Foundation not only allows the parent more peace of mind, but also provides the child with opportunities for a better life."

Nancy Mansfield, Ph.D.

Executive Director, Institute for Families, Patient Advocate, Institute for Maternal & Fetal Health, Children's Hospital Los Angeles:

"Last week I tried other means to help the parents of S. Martinez; a family who drove here from across the country with their 5-month only baby to get medical assistance....I was able to secure medical insurance but failed in my attempts to help them with all other problems. I was concerned about how they would buy food; keep their home while they are here, etc. I made one phone call and filled out one simple form and your foundation made it

possible for this baby to have a parent by his side during his chemotherapy. This little baby can rest with his mom by his side and will not be homeless when his treatment is completed. Your foundation has paid the mortgage on their trailer, their utilities, their insurance and even their phone bill so that this baby can have what he needs, his mom."

Valerie Sobel, Founder

Andre Sobel River of Life of Life Foundation

Valerie Sobel is founder and president of the Andre Sobel River of Life Foundation. Her teenage son died of a malignant brain tumor, and the work Ms. Sobel now embraces was born with the death of this cherished son. The Foundation bears his name because it gives her pleasure to see and hear his name.

Her prior careers have been eclipsed by the passion she feels for the work of the ASRL Foundation. Its mission is to help lone caregivers, caught in the devastating struggle for their terminally ill child. This invisible community - of mostly single mothers have few emotional or financial resources, and little to no support, observes Ms. Sobel.

In her own case, Ms. Sobel did not suffer from a lack of financial or other means. Losing Andre was not the end of all that she was to lose. A year later, to the day, her husband Erwin committed suicide, born of his own grief.* Ms. Sobel struggled in the relationship with daughter, Simone, who felt the emotional abandonment that often strikes siblings when parents must focus nearly fulltime on the needs of a dying child.

Through months of overwhelming pain, Ms. Sobel sought to re-direct her life. Almost as an epiphany, the idea of her mission came to her, "Experiencing the sudden onset of a life-threatening illness of a child devastates every family. But for the single mother without financial resources, it is unimaginable."

Ms. Sobel has created an ever-growing network of affiliated hospitals where their program is delivered through social workers. They identify the

financial crises afflicting their patients and their families, (primarily in the households with only one-caregiver) and turn to ASRL when other resources for assistance have been exhausted. The hallmark of the organization is help in 24 hours. Over the past six years, the Foundation has supported thousands of families. The funds they provide pay for rents and mortgages, groceries, utilities, transportation and burial costs. The Foundation's pioneering work has been the subject of a study by the National Institutes of Health. Ms. Sobel's expertise has led to collaboration currently with Harvard pediatrician, Dr. Elizabeth Rider, in the writing of a book, *Caring for the Caregiver: A Formula for Survival*. Notes Ms. Sobel; "I know what a mother feels and needs, and by caring for her, we care for the child."

Herself a survivor of the Communist era, Ms. Sobel fled Budapest during the 1956 uprising against the Soviet regime in Hungary. She remembers walking eight miles into Austria one night, her younger brother on her back. After passing through refugee camps, Ms. Sobel and her family settled in Toronto, Canada. Many uncertain years were to follow. While still in high school, she was interested in acting and through a fortuitous opportunity, and she was flown to Los Angeles for an audition. She gained the part she was tested for and was introduced in "Mr. Hobbs Takes a Vacation," appearing with Jimmy Stewart. She brought her family from Canada and they became residents of Los Angeles in 1962. Marriage followed, with the birth of her son Andre and daughter Simone. As one who has "the ability to re-invent oneself," Ms. Sobel developed a substantial career as an interior designer, with an international clientele. Her work was featured in several books and magazine publications, including *Architectural Digest*. She remains a member of ASID (American Society of Interior Designers) "as a keepsake from that career."

Today, in addition to guiding the work and expansion of the Andre Sobel River of Life Foundation, Ms. Sobel keeps an active professional schedule. She is a recognized speaker, a trained Court Appointed Special Advocate (CASA), serves as a charter member of the Women of Washington/Los Angeles and is a founding member of the Women's Foundation of California's Donor

Circle. Ms. Sobel also participates in The Women's Leadership Council, the Los Angeles Music Center's Blue Ribbon Society, the Council of Women World Leaders, and member of the Academy of Motion Picture Arts and Sciences.

When not traveling, Ms. Sobel spends time between Los Angeles and her mountain home in Idyllwild, California. Daughter Simone is a student at Lynn University in Florida.