

# 2001

## A Bridge to the Future



### *Mission*

*To seek the cause, improve the clinical treatment and discover the cure of hyperoxaluria and oxalate stone disease and enhance the quality of life of patients and their families.*



The Oxalosis and Hyperoxaluria Foundation

The **Oxalosis and Hyperoxaluria Foundation's** thirteenth anniversary year was marked by the building of bridges between our past and our future. Looking to the past, we recognize with gratitude those individuals who have paved the way. Looking to the future, our vision beholds cures for hyperoxaluria and oxalate stone disease and the hope for their prevention and complete eradication.

Our road map is a new strategic plan, designed over the last year, which touches on every aspect of our mission and operation. Our strategic plan will help accelerate the fulfillment of our mission as we continue our search for cures.

## **Research**

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As fundraising revenue increases, we continue to redefine our objectives for research support, developing increased levels of funding for scientists over an increased period of time. In fiscal year 2001, The Oxalosis and Hyperoxaluria Foundation awarded \$379,915 to scientists at institutions in the United States and abroad - the highest amount ever. This was an increase of 36% from 2000, and 95% over the very humble beginnings of the grant program in 1997 when \$19,455 was awarded.

A major new category of funding designed to accelerate the pace and success of research was announced in 2001. The Clinical Center for Primary Hyperoxaluria at the Mayo Clinic under the sponsorship of The Oxalosis and Hyperoxaluria Foundation will establish a structure for innovative, cooperative trials for hyperoxaluria and oxalate stone diseases that will involve the larger community of interested clinicians and scientists within the continental US and selected foreign representatives.

## **2001 Research Grant Awards**

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- **Renal Oxalate Secretion and Proximal Tubule Injury**  
by Ross P. Holmes, Ph.D., at Wake Forest University School of Medicine, Winston-Salem, North Carolina.
- **Intracellular Oxalate Concentration: Isotopic and Fluometric Determination**  
by Robert W. Freel, PhD. At Northwestern University of Chicago.
- **Expressions of Characterization of Oxalate Decarboxylase. A Potential Therapeutic/Prophylactic Agent for Hyperoxaluria**  
by Nigel G. Richards, Ph.D., B.Sc. (Hons), at University of Florida, Gainesville, Florida.

## **Professional Education**

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As the leader in the fight against hyperoxaluria and oxalate stone disease, The Oxalosis and Hyperoxaluria Foundation provides the medical and scientific communities with the most current and comprehensive research information through conferences, workshops and seminars.

On the national level, the NIDDK in cooperation with The OHF sponsored the 2nd Oxalosis and Calcium Oxalate Stone Disease Workshop, bringing together over 70 participants from all over the world to speak on a variety of cutting edge topics related to oxalosis and calcium oxalate stone diseases.

In addition, members of the The Oxalosis and Hyperoxaluria Foundation Scientific Advisory Board participated as speakers on a session dedicated to Oxalosis at the Pedi-

atric Nephrology Seminar, XXVIII, sponsored by Jackson Memorial Hospital and University of Miami held February 24th and 25th in Miami, Florida.

In September, the OHF attended the 12th International Pediatric Nephrology Association Congress in Seattle, Washington. The session on Urolithiasis and Nephrocalcinosis, sponsored by the OHF was attended by over 500 nephrologists and featured talks by several members of the OHF Scientific Advisory Board.

The OHF also participated as an exhibitor at this event, and as well at the ASN/ISN World Congress of Nephrology in October in San Francisco, distributing informational and educational materials on Oxalosis and the Foundation to attendees from around the world.

## **Patient Services**

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The Oxalosis and Hyperoxaluria Foundation is a direct source of support for patients and those who care about them. Recognizing that a diagnosis of hyperoxaluria can be medically and emotionally overwhelming, the OHF provides a range of informational and support services to help foster a sense of optimism and hope.

During the year, the OHF increased the number of patient support volunteers to serve patients across the US and abroad. By the end of the fiscal year, every region had one or more of these volunteers whom coordinate programs and referrals for patients and their families. Such programs include, the "Patient Support Network", a peer support program which trains survivors and/or

their family members to offer one-on-one support to newly diagnosed patients. Being able to talk with someone "who has been there" is described by many patients as one of the most helpful services available to them. In addition, the OHF provides an email-based mailing list (support group) to discuss topics of interest to the OHF members and others interested in hyperoxaluria and oxalate stone disease. On-call doctors are available to answer medical questions related to these diseases. Furthermore, the OHF offers a variety of educational information and materials free of charge to patients and their families, the public and the healthcare community with accurate, up-to-date information and resources.

## **Public Education**

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The Oxalosis and Hyperoxaluria Foundation is a primary resource for authoritative and current information about hyperoxaluria and oxalate stone disease. In 2001, we placed special emphasis on raising the public's awareness of these diseases, and took a proactive role in advocating for the needs of patients and those who care for them. In

addition, we increased access to our ongoing sources of information, including, the web site at [www.ohf.org](http://www.ohf.org) and the "in touch" newsletter and we expanded their content substantially. By doing so, we are helping to bridge the knowledge gap for patients and professionals as well as the general public.

## **Government and Legislative Affairs**

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The Oxalosis and Hyperoxaluria Foundation is a powerful voice on behalf of patients with hyperoxaluria and oxalate stone disease. In fiscal year 2001, the National Institute of Health agreed to a program announcement of \$1,500,000 (\$750,000 per year for two years) for research specifically in the fields of Primary Hyperoxaluria and related stone diseases. These dollars are available under the R21 Award Mechanism. These funds should enable a vast amount of research to be conducted by investigators in stone disease and further our understanding of the pathogenesis and clinical outcomes of these devastating diseases, and attract new investigators to our field as well.

A major new development, designed to further the understanding of hyperoxaluria and oxalate stone disease, is the announcement by the NIH and NIDDK to offer a mechanism to create and sustain a patient database for primary hyperoxaluria. This database will serve as a valuable resource for scientists and clinicians interested in furthering the understanding of these diseases. The NIH's decision is an outgrowth of the Oxalosis and Calcium Stone Disease Workshop sponsored by the NIDDK in cooperation with The Oxalosis and Hyperoxaluria Foundation and the efforts of our Government and Legislative Affairs activities.

## **About Hyperoxaluria**

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Hyperoxaluria literally means "more than the normal amount of oxalate in the urine." Hyperoxaluria is a potential problem because the excess oxalate may precipitate with calcium in the urine and readily forms crystals and stones in the kidneys. A number of disorders can cause hyperoxaluria. Some of these are inherited (the so-called Primary Hyperoxalurias), while others are acquired and may be due to the dietary intake or specific problems within the intestinal tract that allow increased absorption of oxalate from the diet.

The Primary Hyperoxalurias (PH) are rare metabolic diseases caused by missing liver enzymes that normally

prevent the accumulation of oxalate-forming chemicals in the body. PH-I is caused by a deficiency or an absence of the liver enzyme alanine: glyoxylate aminotransferase (AGT). In PH-II another enzyme, glyoxylate reductase (GR), is deficient or missing from the liver and other body sites. Another small group of patients have unclassified hyperoxaluria that in some may be another inherited form of PH. In all cases, too much oxalate is produced in the body. Stones in the kidneys can cause severe pain, progressive kidney damage and eventually kidney failure and progressive oxalosis, or the body accumulation of oxalate in organs and tissues.

## Financial Highlights

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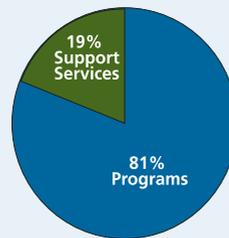
### Fiscal Year 2001 Functional Expenses

Research (71%)

Professional Education (5%)

Patient Programs and Public Education (5%)

Management and General (19%)



The Foundation's consolidated financial statements for the year ended December 31, 2001, including operations of chapter offices located across the United States, have been audited by CB&T, Campbell, Benn & Taylor, an Accountancy Corporation.

The Oxalosis and Hyperoxaluria Foundation is the world's largest private organization concerned solely with finding cures for hyperoxaluria and oxalate stone disease, and enhancing the quality of life of patients and their families. The Foundation's principal activities include awarding research grants, providing emotional assistance to patients and disseminating educational information. In fiscal year 2001, the Foundation awarded \$379,915 in research grants and spent a total of \$432,708 on all programs combined.

The Foundation is a charitable organization as defined by Internal Revenue Code 501(c)3, and accordingly, is exempt from federal income taxes under Internal Revenue Code Section 501(a). Additionally, contributions to the Foundation qualify for the maximum charitable contribution deduction prescribed by the Internal Revenue Code.

The Foundation is an equal opportunity organization. No one is excluded from employment, membership on its governing body, research support, or patient assistance because of race, religion, sex, age, national origin, or physical handicap.

## With Appreciation

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The Oxalosis and Hyperoxaluria Foundation is grateful to the thousands of individuals and organizations who have unselfishly given their time, talent and financial resources.

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