

PXE Awareness

*National Association for Pseudoxanthoma Elasticum
(NAPE, Inc.)*

Volume 14, Issue 1, April 2008



 HEARTILY WELCOMES
**Inauguration of Global PXE
Foundation and International
Consortium On Nanomedicine**

**Dr. Frances Benham
Dr Berthold Struk
Dr Henry White
Ms. Heidi Kevlin
Dr Kattesh V Katti
Dr Raghuraman Kannan
Mr Rama Eyunni**

09.01.08



National Association for Pseudoxanthoma Elasticum (NAPE, Inc.)

8760 Manchester Road, St. Louis, MO 63144-2724

Voice & Fax: 314-962-0100

Email: napestlouis@sbcglobal.net Web: www.napxe.org

NAPE, a non-profit 501(c)(3) support group whose mission is to provide education and support for PXE-affected persons, publishes *PXE Awareness*. Articles in this newsletter are provided for information only and are not a substitute for professional medical advice. You should not use information in this newsletter to diagnose or treat medical or health conditions. Please consult your healthcare provider before beginning or changing any course of treatment.

Board of Directors

Chair/President - Frances Benham, MO

Vice-President – Linda Zeug, MN

Treasurer - Rosemary Atallian, DE

Secretary – Heidi Kevelin, MT

Sally Dawoud, Canada

Brian Kevelin, MT

Claudia McCallister, FL

Lenore Seeuwen, PA

Nancy Testard, IL

Grant Zeug, MN

Board of Medical Advisors

- Wayne S. Fuchs, MD, Diseases of the Retina & Vitreous, New York, NY
- Robert J. Hoehn, MD, FACS Plastic Surgeon, Denver, CO
- Daniel Hohl, MD, Dermatogenetic & Cutaneous Biology, Lausanne, Switzerland
- Kattesh V. Katti, Ph.D., FRSC, Radiopharmaceutical Sciences Institute, University of Missouri-Columbia, MO
- Mark Lebwohl, MD, Dermatology, Mt. Sinai Medical Center, New York, NY
- Klaus Lindpaintner, MD, MPH, VP and Head, Roche Genetics (Europe), Pharmaceuticals Division, Basel, Switzerland
- Kenneth H. Neldner, MD, Dermatology, Lubbock, TX
- Franziska Ringpfeil, MD, Thomas Jefferson University-Dermatology, Philadelphia, PA
- Berthold Struk, MD, Cardiovascular Molecular Genetics, Max-Delbrueck-Center for Molecular Medicine and Franz-Volhard Clinic, Cardiovascular Medicine, Berlin, Germany
- Lawrence Yannuzzi, MD, Manhattan Eye, Ear & Throat Hospital, LuEsther T. Mertz Retinal Research, New York, NY

Table of Contents

President's Message.	4
Glimpses of India	7
Sankara Nethralaya and NAPE	12
Indo-U.S. Collaboration in Health	17
Global Pseudoxanthoma Elasticum Foundation	21
India in Literature	24
PXE Pals.	30
NAPE Membership Form	31
Change of Address Form	32





President's Message

Dear NAPE Friends,

NAPE was pleased to receive Genentech's response to our concerns as to the continuing availability of Avastin. Dr. Arthur Levinson, Chairman and CEO, informed us of Genentech's agreement with the American Academy of Ophthalmology and the American Society of Retina Specialists to assure the supply of Avastin for vision loss treatment. We are deeply grateful and will include details of the plan in the next issue of *PXE Awareness*.



4

This issue focuses on NAPE's new relationship with India's Sankara Nethralaya and about our visit to this remarkable eye care center and to India itself by NAPE Board member Heidi Kevelin, Medical Advisors Drs. Berthold Struk and Kattesh Katti and me. Some may wonder why we should be interested in eye care in another country – and why India.

I hope our reasoning will become clear through this issue. The most pragmatic reason is found in the astonishing services of Sankara Nethralaya. They care for many more patients per week than any Western ophthalmology practice. They turn no Indian in need away. Indeed, they seek out such people through a remarkable program which brings care to rural villages. They focus on vision, but they also pay attention to the whole person. If glasses are needed, they are made on the spot and given without charge. If more demanding care is needed, the patient is brought to the hospital in Chennai where housing, food and medical care are provided. When the patient is well enough to go home, transportation is provided. Almost half of Sankara Nethralaya's patients are cared for in this way. Others who can pay come from all over India, Asia and increasingly from around the globe as word spreads that care here is as good as that in better known centers, that costs are substantially lower and that patients are not simply treated and sent away, but are cared for by skilled professionals until they are well enough to manage their own care.



Because Sankara Nethralaya treats so many patients, it stands to reason that they may have seen more PXE than Western doctors who treat fewer patients. A review of well-kept records of their patient load over the last ten years identified over 170 PXE patients. Dr. Struk, Dr. Katti and I agree that genetic screening of these patients and relatives can help us to understand ABCC6 better and over time to tease out its secrets which cause our problems. Dr. Struk discussed at length with leadership of Sankara Nethralaya's Genetics Department tests important to the process. Sankara Nethralaya can easily handle any and all of these tests and has the latest technology needed to conduct them. It is in the interest of all PXE patients - Indian, American and all others - to pursue this research opportunity. Heidi, Dr. Struk and I came away with the hope that we can help Sankara Nethralaya in some small way to achieve its humanitarian goals. Please read Heidi's traveler's glimpses of India, the article by me on Sankara Nethralaya and the other articles which result from presentations at our conference in Chennai. I hope you will join in our commitment to conduct research which will help all PXE families, and that you may become interested in Sankara Nethralaya and in India too.

This issue does not include all that we planned for it. To keep it to a manageable size, we will include presentations made in India by Drs. Struk and Katti in the June issue. This issue introduces you to what we intend to be a long rewarding relationship with Sankara Nethralaya. We hope you will become involved in this important effort. To help us better understand and appreciate India we have included a reading list prepared for us by reference librarian, Gowri Ravindranath, of the American Consulate in Chennai. I am working my way through it and hope you will join me in learning more about today's India. I am sure you will find the Consulate's Public Affairs Officer, Fred Kaplan's, report on health care cooperation between the U.S. and India informative and interesting.

Over the last few years, *PXE Awareness* has been printed in 18 point type. The Library of Congress considers 14 point type the standard for large print. We have decided to try 14 point type in this issue. Please let us know what you think of it. If needed, we will return to the larger print.



5





Finally, please note the donation envelope. During my tenure as NAPE President since 2001, we have requested donations only twice. We do not press members repeatedly for funds as we know many struggle in mid and late life with vision loss and the increased financial burdens it causes. We work very hard to keep NAPE expenses low. Our Board members' India trip cost NAPE nothing. Board members are asked to pay their own expenses for conferences and to conduct our business. Most also contribute to NAPE. With these things in mind, I am asking those who can to contribute whatever you can to be used for our research efforts. Every penny donated for research is spent for research. Every penny helps us to find needed answers to ABCC6's ability to interfere with our lives. Thanks for whatever you can do in our shared cause.

With all good wishes,

Fran Benham, PhD

6

P.S. The cover features Dr. S.S. Badrinath, about whom you can read in my article about Sankara Nethralaya. The welcome sign greeted us at our conference. The beautiful plate, so evocative of India, was given to me for representing you at the conference. It decorates NAPE's office along with the picture of Jagadhguru His Holiness, Sri Chandrasekarendra Saraswathi Swamigal of Sri Kanchi Kamakoti Peetam, who inspired Dr. Badrinath to found Sankara Nethralaya.



Glimpses of India

By Heidi Kevelin



Heidi Kevelin

We (Berthold Struk, Fran Benham and I) flew out of Berlin on an icy January morning. Many hours and time zones later, we landed on a lovely, warm, tropical morning in Chennai, India. We came to visit Sankara Nethralaya (Temple of the Eye), one of the world's largest eye care centers where needy patients do not hear terms like *insurance*, *co-pays* or *outpatient care*, but are treated with the latest in medical advances no matter their ability to pay. We saw astonishing numbers of patients and staff working efficiently so that all could receive needed attention. And we saw patience, kindness and gentle good humor. We came away humbled and honored to have had such an opportunity. Please read Fran's more detailed article about this remarkable institution after I share some observations and a few of the many photos Berthold and I took as roving reporters.

7

**Dr. Krishnakumar
welcomes
Berthold,
Heidi and Fran**



Where to begin? We had so many memorable experiences - some I am still processing. Let me start by thanking those who planned and provided guides for us. Josh, from Sankara Nethralaya, proved a wonderful guide around Chennai, introducing us to a local shrine, an outdoor market, a church with wedding in progress, the nearby beach on the Bay of Bengal and a busy mall





which rivals any in the West. Josh taught us much about Indian life and customs. Dr. Rashmin Gandhi with his lovely wife, Pritti, led a marvelous tour in the Chennai region, Mysore and Bangalore. His goal was to make sure we saw “the real India.” We believe we did and are most grateful for all that Dr. Gandhi did for us. Those who participated in NAPE’s Atlanta conference will recall the role he played there.

Prior to our trip, we heard that India is densely populated and very poor. Its land mass is about one-third that of the United States while its population of 1.3 billion is more than three times larger than ours. There is poverty, but it should be noted that India’s middle class is as large as the entire U.S. population and growing. So, it is more fair to say that there is wealth and poverty in India just as there is in our nation. India’s economy is growing rapidly compared to our own as India, along with China, is once again emerging as an international trading power, just as both once were when our nation was a cluster of villages on our eastern shore. Yes, India does have much to do to deal with poverty and population. Institutions like Sankara Nethralaya are an important part of the move to improve life for all in India.

8

A very important part of any culture is its food, and India lives up to its reputation for exotic delicious foods. The cuisine, mostly vegetarian, is highly varied. Those who enjoy hot spicy dishes (like Berthold Struk) will be delighted, and those who prefer milder fare will find that too. Fresh fruits - mangos, pineapple, bananas, coconut, apples, citrus and various melons - are widely available. Desserts we had never encountered before, like a wonderful sweet carrot custard served with ice cream, inspire our hope to replicate them at home. The various breads were wonderful, and we were surprised and pleased with the many ways rice is presented, including in breakfast pancakes served with a delicious lentil sauce. Western food choices were available, but we loved eating the delectable Indian way.

Travel in India is an adventure. The old rickshaw is now a small three-wheeled motor-driven vehicle. These mustard-colored vehicles are everywhere, providing inexpensive transportation for short trips. A more exciting trip is available by motor scooter. One sees groups of two, three or four people tooling along in heavy traffic all perched on these little bikes which zip in and out of small openings in the traffic stream, which fortunately is not moving too



rapidly. Interspersed with these small vehicles are autos, vans, huge buses and trucks - lots of honking horns and more than a little exhaust smoke filling the crowded city streets. It is noisy, exciting and at times a tad stressful, but surprisingly seems to result in few accidents. And along the sides of the busy streets are throngs of people on foot. Getting across those streets requires speed and daring. Locals seem to take it all in stride, but to us it was part of the excitement and made us feel brave indeed!



India is colorful! One quickly notices, for example, bright creative decorations on the buses which provide mass transit. One also quickly sees that men's clothing is quietly conservative while women wear beautiful and colorful dress. Younger women tend to wear more western styles with distinctive Indian touches - most notably the lovely fabrics. Fran and I could not resist adding Indian outfits to our own closets. I greatly enjoy the comfort and beauty of mine which I wear regularly.

Education is a great value of Indian life. A common sight is children in school uniforms wearing backpacks on their way to school. We learned that most children attend school and that doing well is prized. As in our own country, Indians use education to improve opportunity. Science and math seem to receive more attention than in our schools, and India's scientific and technical successes are playing a major role in the improving economy. At Sankara Nethralaya we were pleased to meet quite a number of women physicians and scientists.

9



N A
P E

Shrines and temples, ancient and modern, attest to a thriving spiritual life among Indian people. We visited temples that were old before Columbus, looking for a short passage to India, found instead what became the Americas. Such temples still draw many worshippers.



Indian family ties are strong. Parents play an active role in the choice of a spouse for their children. Older people are treated with respect. Fran got a kick out of being addressed as “Mama” by merchants who offered her a chair and brought their wares to her. She was surprised by people who asked to take photos with her and by children who wanted to talk to her. She says these will remain among her cherished memories of India.

10

Our travel included a van with local driver, a train and air travel. We covered many miles through villages and farmlands. We saw fields being worked by the most modern tractors and others by bullock-pulled plows. Cattle, goats and other animals wandered about freely though we were told that the number is lower than in the past as modern life has decreased space and nourishment for them.



N A
P E

Indian men, like their American counterparts, are crazy about sports - and cricket tops all others. Several TV channels seem to broadcast it day and night. And ladies, imagine this, a match can last all day!



India's democracy seems as messy as our own. Chennai boasts six newspapers which carry political as well as other news. TV newscasts, including a version of CNN, provide national and international coverage. That about the West seems objective - perhaps more so than what we get at home. Those we met are deeply interested in their local and national leadership and in that of other nations.

We witnessed the roll-out of the Nano, a mini car which meets safety standards at a cost of \$2500. A family of four, perched precariously on a motor scooter, may find these cute minis quite roomy. The Nano is but one example of how inventive Indians are solving problems as they move toward prosperity.

I could go on and on about remarkable India. I learned that Indians and Americans are much alike. Our lives differ in the details, but at the human core, we want and seek the same things. We can learn much from these strong, fully alive people. We are grateful for our opportunity with them, and we wish them only the best.

11



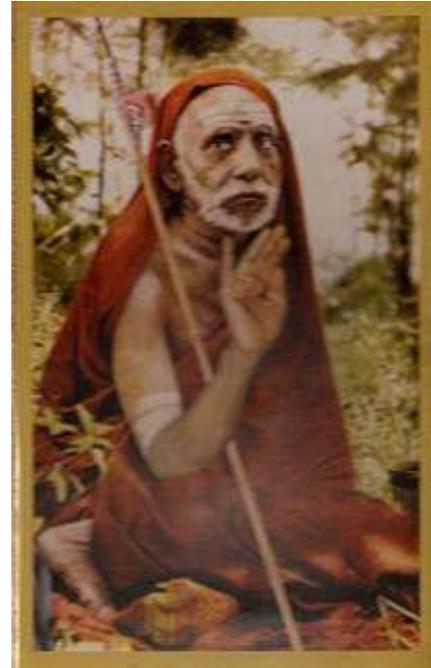


Sankara Nethralaya and NAPE

By Fran Benham

12

Sankara Nethralaya (SN) was founded in 1978 by a young physician fresh from his medical studies and training in the United States. Like many Indian graduates in medicine, science and engineering, Dr. Sengamedu Srinivasa Badrinath could have stayed in the U.S. to enjoy a lucrative career. He chose instead to respond to the call of Indian spiritual leader, Jagadhguru His Holiness Sri Chandrasekarendra Saraswathi Swamigal of Sri Kanchi Kamakoti Peetam, who urged him to return home to care for the people of India. Dr. Badrinath established Sankara Nethralaya (Temple of the Eye) in Chennai, starting in small quarters treating with equal care those who could pay and those who could not. The need was great and as word spread the practice grew. Today this eye care hospital, based on a commitment to do God's work, fills a large complex with a multistory building currently under construction. Two other facilities have been opened in other locations. Some 1,500 patients are welcomed and 125 surgeries are performed each day. Just over half those treated pay for their care with the remainder treated according to need at no charge.



**His Holiness, Sri
Chandrasekarendra Saraswathi
Swamigal of
Sri Kanchi Kamakoti Peetam**

Rural out-reach, a primary objective of SN, is achieved with missionary zeal, as huge vans equipped with medical technology travel to villages to test and treat all who ask. Glasses are made for those who need them. Medications and education are provided. Those with more complicated ailments are brought to Chennai where they are housed, fed and treated. When well enough, they are returned home. Those who need continuing care receive it. SN's work is widely recognized, and Dr. Badrinath and his staff are deservedly revered throughout the nation by those who gratefully turn to them in their time of need.



The staff includes not only most specialties in ophthalmology, but also specialists to care for the whole person. And, in an effort to constantly improve, there are departments of microbiology, histopathology, molecular biology, ocular pathology, biochemistry, genetics and infectious diseases. They work with attending physicians in research to better understand and treat disease processes.



Dr. Berthold Struk consults with Dr. S.S. Badrinath

SN engages actively in a variety of collaborative projects with highly prestigious organizations in the U.S., Japan, New Zealand and Hong Kong. Among them is the U.S. National Eye Institute of the National Institutes of Health, as well as medical schools and pharmaceutical companies. SN's eye gene disorder identifications contributed to the Human Genome Project. Significant research is underway in adult onset cataract, glaucoma, diabetic retinopathy and retinoblastoma. Improved diagnosis and treatment are the objective as large numbers of patients are treated for these disorders each

year. As example, 20,000 cataract surgeries are performed every year. SN's Eye Bank has received over 4,000 donor eyes and restored sight to over 3,000 patients in need of corneal transplants. Corneal tissue not useful for transplant is used for research. Peer reviewed research published papers inform scientists and physicians around the world of these and other SN discoveries.

SN's normal work week is six days with only one day for rest. Attending physicians may consult with fifty patients each day. This is possible through remarkable organization, excellent committed staff and the most current technology and know-how. Focus is on what is important - no ostentation - no pretension. Indeed SN's approach is so quietly understated that the uninitiated might not realize they are in the presence of as highly educated, qualified,



experienced and confident a medical organization as can be found anywhere.

Never satisfied, another primary value of SN is training. Staff travel globally to study best practices and new discoveries. Those which are appropriate are incorporated into SN practice and shared with colleagues across India. Dr. Badrinath's wife, American board-qualified pediatrician, S. Vasanthi Badrinath, MD, Director of the Clinical Laboratory of SN, exemplifies the drive for improvement as she, in addition to leadership duties, currently is training in Hematology. In addition to staff development as a given, SN is certified for and has trained in its residency program hundreds of ophthalmologists who are practicing physicians in India and abroad. SN also is certified to prepare candidates in ophthalmology, microbiology and biochemistry for the PhD degree.

14

The potential for research on PXE at SN is tremendous. Dr. Kattesh Katti - raised in India, educated there and in Europe, and today a medical school professor at the University of Missouri, Columbia, in the U.S. - brought this to our attention. In the U.S. rare disorders like PXE receive little attention unless they have strong well-financed advocacy groups, and even then research commitments are hard to come by. Most physicians in the U.S. and the West in general, including those in schools of medicine, see relatively few patients with PXE. Their patient loads are small compared to that of SN.



Dr. Kattesh Katti

Interestingly, in the West the PXE patient load includes about twice as many females as males. Speculation around this fact centers on whether PXE is a female disorder or if males are just less likely to seek diagnosis and treatment. SN's records of the last ten years identify over 170 PXE patients, just over half of them male, in keeping with India's overall population. This suggests that when medical care is readily available, the ratio of female/male PXE is what one would expect. If we in the U.S. are ever



successful in securing universal health care, perhaps our PXE patient load will also reflect our population. SN offers a model which might help us achieve that desirable goal.



The large number of PXE patients in the care of SN (plus those who will continue to be identified) represents a researcher's dream. This reporter had the privilege of sitting with Dr. Berthold Struk as he discussed possible research with Dr. G. Kumaramanickavel, head of SN's Department of Genetics and Molecular Biology, and his colleagues. This group has the knowledge, experience and technology to conduct every test and procedure which collectively can add greatly to our understanding of how and why ABCC6 functions to cause us grief.

But, PXE is not SN's biggest concern either. They perform thousands of cataract surgeries each year, treat many glaucoma patients and care for large numbers of diabetic patients. Diabetes is an example of a disorder which takes a terrible toll in India. For many thousands of years, India has suffered intermittent famine. Over eons, those who survived famine evolved body chemistries that allowed them to live on the smallest amounts of food and water. Today, India is much better able to provide adequate nutrition for its population even when crops fail. The chemistry that kept people alive in times of famine is now a health problem for many, large numbers of whom suffer from diabetes, and among other serious health effects, diabetic retinopathy resulting in blindness. The scientists of SN are conducting important research in this area - research which will help people all over the world. Dr. Struk noted that natives of what became the American Southwest, also subject to periods of famine, experienced the same evolution. Today, that population also suffers disproportionate levels of diabetes and will benefit from SN's research in diabetic retinopathy.

15

With so few cases of PXE relative to a high rate of diabetic retinopathy, cataract, glaucoma and other disorders, SN must focus first on them. Even so, the scientists of SN are willing to collaborate with NAPE. To introduce a focus on the inheritance of PXE and its genetic process requires skilled personnel for many tasks and labs equipped to run tests and experiments, analyze results and much more. The good news is that research is less expensive in India than in the U.S. or in Germany where Dr. Struk works. We inaugurated the Global PXE Foundation at SN to





develop funds for this research (see Dr. Rashmin Gandhi's article). Already we have been promised help, but we need more before we can support the personnel, equipment, supplies, etc, necessary. We are deeply grateful to Dr. Badrinath and his staff for their willingness to work on PXE when they have so much else to do. NAPE has an unparalleled opportunity to help bring the brilliant scientists of Sankara Nethralaya, Berthold Struk, MD, (who also holds the PhD in genetic studies from Harvard), Kattesh Katti, PhD, and his associate Raghuraman Kannan, PhD, both from the University of Missouri-Columbia, together in collaboration with SN's remarkable source of potential patient donors.

16

NAPE has always been a quiet group, focused and determined. Members can recall that we helped support the first important research since PXE was recognized as a specific disorder. That study by Ken Neldner, MD, provided the first detailed scientific description of PXE. A copy of the book which resulted from his study was presented to Dr. Badrinath for SN's fine medical library. The second NAPE supported study was that conducted by Berthold Struk at Harvard. A young physician fresh from his cardiology training in Germany, Dr. Struk studied at Harvard for seven years with much attention centered on his successful search for the PXE gene. The lab which led to his discovery started because Dr. Neldner, after approaching numerous possible donors, finally met Dr. Klaus Lindpaintner whose company, Roche Genetics of Switzerland, provided funding. Drs. Neldner and Struk worked with NAPE members to collect DNA samples and family histories for the study. Since his identification of ABCC6, achieved also by three other labs which worked from his published announcement of the gene locus, Dr. Struk has continued to study ABCC6, to care for PXE patients and to share his knowledge with other scientists and physicians.

We of NAPE feel a kindred spirit with the family of SN because they see problems and work quietly to solve them. That is also the story of NAPE, admittedly on a much smaller scale. We are focused on the specific goals of educating those who face life with PXE and the support of PXE genetic research. We believe understanding ABCC6's functions and malfunctions is key to a cure. NAPE's Board decided in 2001 to support Dr. Struk as best we can. He is vital to NAPE's goals, and we have quietly raised funds for his efforts. We are honored to do this, and now we have the great honor to support his collaboration with the remarkable



scientists and physicians of SN and also with the internationally renowned Nanomedicine group of scientists, Dr. Kattesh V. Katti and his associate, Dr. Raghuraman Kannan – all of whom share a common spirit of discovery in the interests of humanity.



Over the years since Dr. Neldner's initial study, NAPE leaders have met many of his 100 study participants. They share with pride their part in that study. NAPE members whose families were DNA donors for Dr. Struk's research identify their participation with equal pride. All feel that they helped establish the basic knowledge which eventually will lead to a cure. We of NAPE can bring that dream closer by supporting the funding of our collaboration with SN. All funds received by NAPE for research go to research. We take no administrative fee from donations. We ask our members and others who read about this effort to help as they can. Collectively we will march to the cure with our dedicated scientists and physicians.

Indo-U.S. Collaboration In Health

By Fred Kaplan

17

Editor's Note: Fred Kaplan, Public Affairs Officer, U.S. Consulate General, Chennai, India, spoke at the inauguration on January 9, 2008, of the Global Pseudoxanthoma Elasticum Foundation and the International Consortium on Nanomedicine. His description of some of the many collaborative programs between United States and Indian institutions places our new effort in context among significant programs blossoming throughout both nations. His presentation follows.

I am delighted to be a part of this very important program and am honored to be among so many distinguished physicians and scientists. This program has come at an opportune time. As some of you already know, the American Secretary of Health and Human Services, Michael Leavitt is visiting India this week. On Monday he was in Chennai, Tuesday Hyderabad, today Kochi and tomorrow New Delhi. He is being hosted by the Indian Minister of Health and Family Welfare, Dr. Anbumani Ramadoss. This is the third time they have met in the last year or so.





You might ask, what is going on between India and the United States that requires such close collaboration? The answer, to put it very succinctly, is a lot. Most of it is done privately, and Sankara Nethralaya is a perfect example of that. But as a government representative, I'll talk mainly about what the U.S. Government is doing in the area of public health cooperation. Over the past few decades India and the United States have worked together in the areas of leprosy, malaria, polio, tuberculosis, HIV/AIDS and childhood and oral cancers. This collaboration is in the form of technical support and capacity building not only with the Ministry of Health and Family Welfare, but also with the Ministry of Science and Technology and Ministry of Agriculture.



**Frederick Kaplan with
Dr. S.S. Badrinath**

18

The American Department of Health and Human Services and the U.S. Agency for International Development provide close to \$100 million in health-related assistance to India every year. We have a number of bilateral agreements, and nearly 250 Indian scientists are currently involved in short-term or long-term training in the United States.

U.S. Health Secretary Leavitt is here now because we want to find ways to further increase our cooperation. His first stop was the Government Hospital of Thoracic Medicine in Tambaram. That hospital treats more than 30,000 people each year who are living with HIV. They come from Tamil Nadu, Andhra Pradesh and other states. The American Center for Disease Control, based in Atlanta and which I'm sure you all know, provides technical support to the hospital in three areas: (1) strengthening the quality of laboratory services, (2) transforming patient data management to make it computer-based rather than paper-based, and (3) making the hospital into a national model for providing high-quality and comprehensive care and treatment for HIV patients. Secretary Leavitt interacted with doctors and



patients, including children. He also spoke to the many dedicated Indian scientists and public health specialists working so successfully at that hospital.



Also on Monday, Secretary Leavitt visited Loyola College's Red Ribbon Club. You are probably asking: what is a Red Ribbon Club? It is a model program to teach students how to avoid becoming HIV positive. Currently more than 800 colleges in Tamil Nadu have Red Ribbon Clubs reaching more than 100,000 students. There is a potential to reach more than 750,000 college students in the state. Prevention is of course of paramount importance in defeating the HIV/AIDS epidemic. The Red Ribbon Club students at Loyola College acted out a skit they themselves wrote to educate their peers about HIV/AIDS prevention, showing how the abuse of drugs and alcohol often lead to unsafe sex. Secretary Leavitt formally released a new curriculum called "Celebrating Life." His message to the students on the curriculum was: "Don't just read it, heed it."

In Hyderabad Secretary Leavitt visited Dr. Reddy's Laboratories and Bharat Biotech International. Dr. Reddy's Laboratories produce generic pharmaceuticals for export to the United States. Secretary Leavitt was able during the visit to observe first-hand the safety and quality control measures that Dr. Reddy has put in place. Bharat Biotech is collaborating with the U.S. Center for Disease Control on a very exciting public-private initiative to develop a rotavirus vaccine. The project has the potential to prevent the death of hundreds of thousands of infants in India and around the world.

Secretary Leavitt made the point that the safety of food and drug imports is a more critical issue today than ever before. The United States imports more than \$2 trillion-worth of products from overseas. It is essential that we ensure the quality and safety of those products. Those who produce unsafe or poor quality goods will be punished by the market, and that punishment will be swift and harsh. So the U.S. and India should work together to protect our peoples and our brands – Brand India and Brand America. Once your brand is tarnished, it is hard to win back customers. With respect to food and drug imports, it is not only a health issue and social issue, it is also an economic issue.





Indo-U.S. cooperation in health has gone on for at least the last 35 years, and it is increasing all the time. The National Institutes of Health in the United States has provided funding for over 180 research projects in India. That is a marked increase over time, from zero in 1990 to 17 in 1998 and 67 in 2003. These research grants are contributing to the fight against HIV/AIDS, tuberculosis, malaria and rotavirus.

Meanwhile, the U.S. Centers for Disease Control is one of the largest supporters of polio eradication in India. Before the implementation of polio vaccination campaigns in India, there were an estimated 30,000 annual cases of paralytic polio. With the successful implementation of the Polio Eradication Initiative, or PEI, the number of cases decreased to a historic low of 265 in the year 2000. Unfortunately, there was an outbreak in 2002 but the number for 2007 is around 500 polio cases. One of our main weapons in the fight is to intensify efforts to deliver the vaccine to the 165 million children under 5 years old. We are committed to staying the course and providing the best qualified polio experts in the world until polio is entirely eliminated from India.

20

I am not going to stand here and give you a comprehensive list of all of our cooperative programs. That would take more time than we've got. I just wanted to mention a few programs by way of illustration. Interesting to this audience, one of the areas where India and the United States work together is ocular diseases, including the prevention of blindness. The main point of this, and of Secretary Leavitt's visit to India, is that controlling disease and improving people's health is a global project. It is not a matter of acting only in this country or that. We have to look at the world as a whole because, as we know, disease is no respecter of national boundaries. PXE is an obvious example, showing that disease has no nationality and carries no passport. It goes wherever it wants.

India and the United States are natural partners. This conference certainly exemplifies this, where we see Indian and American clinicians and scientists working together on PXE and in nanomedicine. And it's especially wonderful to see people with PXE, like Dr. Benham and her colleagues, who have dedicated their lives to helping others with the same condition. I tend to believe, though I have no supporting evidence, that such generosity has therapeutic value and results in longer, better and



happier lives for those who practice it. On behalf of my government, I would like to congratulate you on the work you are doing.



India and the United States are both great countries, but together we are even greater. Although the extent of our cooperation in public health, medicine and many other fields is vast, in reality we have barely scratched the surface as to what is possible. There is much more to do, and those working on PXE are on the cutting edge.

I wish you all the best as you work for a better and healthier future for all of us.

Global Pseudoxanthoma Elasticum Foundation

By Rashmin Gandhi, MD

21

Editor's Note: Dr. Rashmin Gandhi spoke on behalf of Sankara Nethralaya at the program on January 9 in Chennai, India, announcing the Global Pseudoxanthoma Elasticum Foundation.

The purpose of this foundation is to support the Pseudoxanthoma Elasticum research program initiated at Sankara Nethralaya. This eye care center has identified in its records over 170 patients who have PXE. These patients will be contacted for possible genetic study and counseling. As well, patients identified currently and in the future who present angioid streaks will be tested for PXE, and if so identified, they will be invited to participate in the study and will receive counseling regarding the inheritance and care for this disorder. These patients will be followed for as long as they need help, and the results of the study will provide information to be used by the genetics



Dr. Rashmin Gandhi





team at Sankara Nethralaya in collaboration with Dr. Berthold Struk.

Dr. Gandhi, a cataract specialist, met with NAPE for its Atlanta conference. Those present will recall conversations with him about PXE and other vision issues. Following is the text of Dr. Gandhi's report.

Global PXE Foundation (GPF) For Clinical Care And Research

GPF is a non-profit global organization committed to enhancing the awareness, clinical care, and research toward helping PXE patients worldwide.

MISSION STATEMENT

22

Our mission is to bring together expertise and influence of eminent individuals within the private and public sector domain to work synergistically for the common good of PXE patients.

ROLES

- Foster educational activities, basic science/clinical research and care toward helping the PXE patient population worldwide.
- Promote communication among the public, patient population and clinicians about available diagnostic and treatment options.
- Create and maintain a database comprised of symptoms, diagnostic tools, treatment options, and clinical outcomes of PXE patients worldwide
- Disseminate scientific knowledge about PXE through symposia, publications and other electronic and print media
- Assist PXE associations at regional, national and international levels in identification of various treatment options for the care and well being of PXE patients



OBJECTIVES

- Create awareness within public and private sectors about PXE
- Help policy makers globally to invest resources for developing new clinical modalities and treatment options
- Establish consortia incorporating active clinical and basic sciences research groups



SCHOLARSHIP

GPF will provide scholarship and training activities for medical students/scientists with interests in PXE clinical and basic sciences research every year.

Scholarship name will be decided by the Board of GPF.

ANNUAL AWARD

GPF will administer an annual award recognizing excellence in clinical care and basic sciences research that directly impact care and treatment of PXE patients.

Annual award name will be decided by the Board of GPF.

23





India In Literature

By Gowri Ravindranath

Editor's Note: Reference Librarian, Gowri Ravindranath, at the American Consulate in Chennai, India, responded to my request for current works of fiction and nonfiction that might help American readers better understand today's India. NAPE readers who obtain much of their reading material through the National Library Service for the Blind will find that the collection of books available about India is quite dated and while it is useful and interesting, most titles end with the demise of British control in India in 1947. This list is offered to NAPE readers who may wish to understand more about this emerging power in our world. We are grateful to Gowri Ravindranath for preparing the list.

Non-Fiction

24

A Concise History of India

by Barbara D. Metcalf, Thomas R. Metcalf, Cambridge University Press, 2001

"With an informative, scholarly text enhanced with illustrations and quotations... recommended for academic reading lists and reference collections as well as the non-specialist general reader with an interest in understanding India's contemporary political and economic relationships with the community of nations..." Library Bookwatch

India: Emerging Power

by Stephen Philip Cohen, Brookings Institution Press, 2002

"A must for all who want to understand India's emerging place in the region and the world" - Ambassador Thomas R. Pickering, former U.S. Ambassador to India

India: From Midnight to the Millennium and Beyond

by Shashi Tharoor, Arcade Publishing, 2006

"At the stroke of midnight on August 15, 1947, a new nation was born. It has 17 major languages and 22,000 distinct dialects. It has over a billion individuals of every ethnic extraction known to humanity.... Shashi Tharoor's India is a fascinating portrait of one of the world's most interesting countries, its politics, its mentality, and its cultural riches. But it is also an eloquent argument for the importance of India to the future of America and the industrialized



world. With the energy and erudition that distinguished his prize-winning novels, Tharoor points out that Indians account for a sixth of the world's population and their choices will resonate throughout the globe." – Amazon.com



India: A Wounded Civilization

by V.S. Naipaul, Vintage, 2003

"Typical Naipaul—brilliantly lucid, terse, with something hardbitten yet resigned in the emotional background." – The New York Times Book Review

India after Gandhi: The History of the World's Largest Democracy

by Ramachandra Guha, Ecco, 2007

"A political narrative of India's six decades of independence, Guha's history emphasizes how the country has remained a mostly territorially intact and constitutional state, despite the expectations of many after the Union Jack was lowered in 1947. An able and readable scholar, Guha proceeds chronologically from the violence-wracked partition of that year to the present, when elections became "indigenized," as did another support to democracy, India's professional, apolitical military. Guha's history, though, is not an uncritical paean to his country. It covers political complexities revolving around caste, language, class, and religion. Instances of conflict arising from their frictions, as in India's contest with Pakistan over Kashmir, illustrate the centrifugal problems with which India's modern founders had to cope. Although the Nehru-Gandhi dynasty is necessarily prominent in Guha's treatment, Guha does not neglect less-famous historical actors, such as home minister Vallabhbhai Patel in the late 1940s, who also set India on course for a democracy that functions, despite imperfections and corruption. A fluent, judicious modern history for general interest." - Taylor, Gilbert, Booklist

25

India Arriving: How This Economic Powerhouse Is Redefining Global Business

by Rafiq Dossani, AMACOM/American Management Association, 2007

"Once the jewel in the crown of the formidable British Empire, India has been surrounded by myth for years. After gaining independence in 1947, this often misunderstood country found itself faced with a new sense of freedom -- and along with it,





enormous burdens and challenges. ... Honest and revelatory, India Arriving provides a deeper understanding of a country that promises to be the next major player in the world economy.” – Amazon.com

India in Slow Motion

by Gillian Wright and Mark Tully, Penguin Books India, 2004
“In everything he writes, Tully’s sympathy for and knowledge of India shines through... He is, indeed, incomparable among foreign observers of that bewildering, maddening, utterly enchanting medley of peoples” -Geoffrey Moorhouse, Guardian

In Spite of the Gods: The Rise of Modern India

by Edward Luce, Abacus, 2007
“Superb. . . . The blend of anecdote, history, and economic analysis makes In Spite of the Gods an endlessly fascinating, highly pleasurable way to catch up on a very big story.” - William Grimes, The New York Times

26

India Unbound: From Independence to the Global Information Age

by Gurcharan Das, Anchor, 2002
“Insightful guide to a rapidly changing nation . . . Something tremendous is happening in India, and Das, with his keen eye and often elegant prose, has his finger firmly on the pulse of the transformation.” - The New York Times Book Review

The State of India's Democracy

by Sumit Ganguly, Larry Diamond, Marc F. Plattner (Editors),The Johns Hopkins University Press, 2007

“The newest volume in the acclaimed Journal of Democracy series examines the state of India's democracy. As India marks its sixtieth year of independence, it has become an ever more important object of study for scholars of comparative democracy. It has long stood out as a remarkable exception to theories holding that low levels of economic development and high levels of social diversity pose formidable obstacles to the successful establishment and maintenance of democratic government.” -

Amazon.com



Temptations of the West: How to be Modern in India, Pakistan, Tibet, and Beyond

By Pankaj Mishra, Picador, 2007

“Fascinating . . . Pankaj Mishra's travels are interwoven with pungent commentary on modern politics in South Asia. . . . This is not a gentle book, but it is a brave one.” –The New York Times Book Review



The World is Flat

by Thomas L. Friedman, Picador, 2007

“Captivating . . . an enthralling read. To his great credit, Friedman embraces much of his flat world's complexity, and his reporting brings to vibrant life some beguiling characters and trends, . . . The World is Flat is also more lively, provocative, and sophisticated than the overwhelming bulk of foreign policy commentary these days. We've no real idea how the twenty-first century's history will unfold, but this terrifically stimulating book will certainly inspire readers to start thinking it all through.”
- Warren Bass, The Washington Post

27

Fiction

The Elephanta Suite: Three Novellas

by Paul Theroux, Houghton Mifflin, 2007

“The dismayed, disoriented American travelers in this trio of stereotype-shattering novellas from Theroux (following Blinding Light) lament the missing solemn pieties and virtuous peasants of the India they read about in novels.”

English, August: An Indian Story

by Upamanyu Chatterjee, New York Review Books Classics, 2006

“A best-seller when it was first published, in India in 1988, this satiric novel chronicles the reluctant coming of age of a privileged young man who has just entered the prestigious Indian Administrative Service. . . . Chatterjee's story is uniquely Indian, as he plumbs his hero's fear of being "just one more urban Indian bewitched by America's hard sell in the Third World.” - The New Yorker





A Fine Balance (Oprah's Book Club)

by Rohinton Mistry, Vintage, 2001

“The setting of Mistry's quietly magnificent second novel (after the acclaimed *Such a Long Journey*) is India in 1975-76, when Prime Minister Indira Gandhi, defying a court order calling for her resignation, declares a state of emergency and imprisons the parliamentary opposition as well as thousands of students, teachers, trade unionists and journalists. These events, along with the government's forced sterilization campaign, serve as backdrop for an intricate tale of four ordinary people struggling to survive.” Publishers Weekly

The God of Small Things

by Arundhati Roy, Flamingo, 1997

“... as subtle as it is powerful, a novel that is Faulknerian in its ambitious tackling of family and race and class, Dickensian in its sharp-eyed observation of society and character.” - Michiko Kakutani, New York Times Book Review

28

Inheritance of Loss

by Kiran Desai, Grove Press, 2006

“Desai's second novel is set in the nineteen-eighties in the northeast corner of India, where the borders of several Himalayan states - Bhutan and Sikkim, Nepal and Tibet - meet. Briskly paced and sumptuously written, the novel ponders questions of nationhood, modernity, and class, in ways both moving and revelatory.” - The New Yorker

Interpreter of Maladies

by Jhumpa Lahiri, Houghton Mifflin, 2000

“...Lahiri's subtle, bittersweet ending is characteristic of the collection as a whole. Some of these nine tales are set in India, others in the United States, and most concern characters of Indian heritage.” – Amazon.com

Malgudi Days

by R. K. Narayan, Introduction by Jhumpa Lahiri, Penguin Classics, 2006 “India's great novelist presents “a gallery of colorful characters” in this collection of short stories set in the mythical village of Malgudi. LJ's reviewer found the tales “compelling miniature gems” From Library Journal. All books of R.K. Narayanan are recommended



Midnight's Children: A Novel

by Salman Rushdie, Random House, 2006

“Extraordinary . . . one of the most important novels to come out of the English-speaking world in this generation.” –The New York Review of Books

“The literary map of India is about to be redrawn. . . . Midnight’s Children sounds like a continent finding its voice.” The New York Times

Naalukettu : The House Around the Courtyard

by M.T. Vasudevan Nair, Gita Krishnankutty (Translator)
Oxford University Press, 2007

“Naalukettu: Stone Courtyard is the story of a young boy, Appunni, set in a matrilineal Nair joint family (a taravad) in the author’s native village, Kudallur. Fascinated with accounts of the prestigious Naalukettu taravad from which his mother was expelled, Appunni visits the house only to be despised and rejected by all. Appunni grows up to earn enough money and returns to buy his ancestral home, but his victory soon turns into ashes when his father’s murderer turns out to be the same man who was the only sympathetic adult in Appunni’s lonely teenage years.” – Amazon Review

A Suitable Boy : A Novel

by Vikram Seth, Perennial Classics, 2005

“Seth previously made a splash with his 1986 novel in verse, The Golden Gate. Here he abandons the compression of poetry to produce an enormous novel that will enthrall most readers; those who are fazed by a marathon read, however, may gasp for mercy. Set in the post-colonial India of the 1950s, this sprawling saga involves four families - the Mehras, the Kapoors, the Chatterjis and the Khans - whose domestic crises illuminate the historical and social events of the era. Like an old-fashioned soap opera (or a Bombay talkie), the multi-charactered plot pits mothers against daughters, fathers against sons, Hindus against Muslims and small farmers against greedy landowners facing government-ordered dispossession.” Publishers Weekly





PXE Pals

To help protect the privacy of our PXE Pals online, please call the NAPE office at 314-962-0100 to request a contact.

30



National Association for Pseudoxanthoma Elasticum

8760 Manchester Rd., St. Louis, MO 63144-2724

Donations - Membership

No membership fee is required, although donations are needed to pay operational expenses, including telephone, fax, email, website and newsletter services.

Donations can be made in Honor or Memory of a loved one, for the Research Fund and/or for the Low-Vision Fund. All donations are tax deductible in the USA.

Operations Honor Memory Low-Vision Research

Name of Loved One: _____

Address for Acknowledgement: _____

PLEASE COMPLETE THE SECTION BELOW IF YOU HAVE PXE, THINK YOU HAVE PXE,
OR ARE FILLING THIS OUT FOR SOMEONE ELSE

Name: _____ Phone: _____

Email: _____ Fax: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Male Female Birthdate: _____ Age: _____

I am diagnosed with PXE Yes No Newsletter: Print CD

Are you legally blind? Yes No Email notification

Do others in your family have PXE? Yes No If so, who? (Mother, Father, Sibling, etc. & Name) _____

Please list any medical problem(s) you are experiencing: e.g., eye involvement, skin lesions, heart problems, gastric bleeding, etc., and comments/questions (use another page if required):

Are you willing to be contacted by another who wishes to talk with someone else who has PXE? Yes No

Have You Changed Your Address?

Please help by letting us know. Please be sure to print your new zip code number, including the extra four digits, if possible. When we use the full zip code, our costs of mailing in the United States are lower. Please help.

New Address

Name: _____

Street: _____

City, State, Zip _____

Old Address

Name, if different: _____

Street: _____

City, State, Zip _____

PLEASE PRINT NEATLY

National Association for Pseudoxanthoma Elasticum
NAPE, Inc.
8760 Manchester Road
St. Louis, MO 63144-2724

ADDRESS SERVICE REQUESTED