Symposium on Primary Hyperoxaluria

Introduction, Scope of the Problem & Need to Heighten Awareness
Dr K S Nayak

Genetics,Enzymatics,Clinical Features And Medical Management
Dr Arvind Bagga

Focus On Adults,And Medical Aspects Of Combined Liver & Kidney Transplants
Dr Dharmesh Kapoor

Surgical Aspects And King's College Data of Combined Liver-Kidney Transplants For Primary Hyperoxaluria
Dr Mohd Rela

ISOT
Indian Society of Organ Transplantation

Combined Liver Kidney Transplant - Liver Experience
Dr A Soin

Dr Golding Bird

Golding Bird (1814 – 1854) was a British doctor and a Fellow of the Royal College of Physicians

He became an authority on kidney ailments and published a comprehensive paper on urinary deposits in 1844

He was also notable for his work in related sciences, especially the medical uses of electricity and electrochemistry

From 1836, he lectured at Guy's Hospital and published a popular textbook on science for medical students called: *Elements of Natural Philosophy*

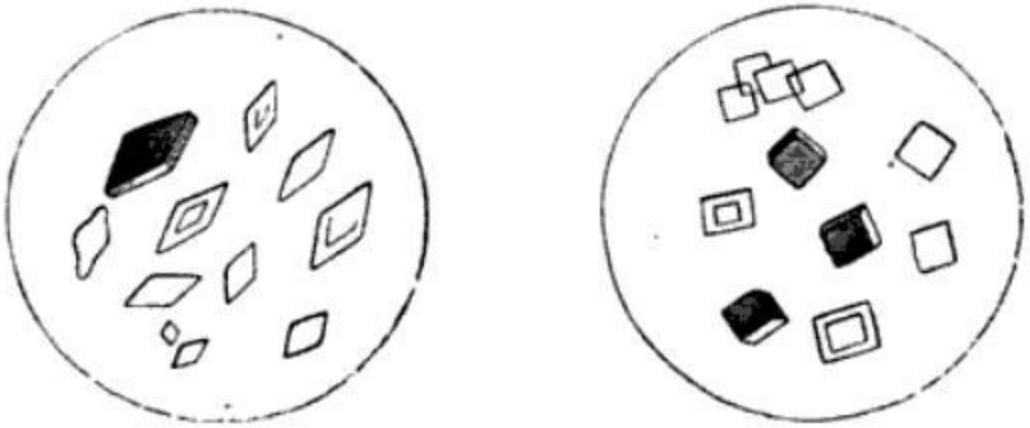
Bird's Disease

In 1842, Dr Golding Bird became the first to describe Oxaluria, sometimes called Bird's disease

In his great work *Urinary Deposits*, Bird devoted much space to the identification of chemicals in urine by microscopic examination of the appearance of crystals in it. He showed how the appearance of crystals of the same chemical can vary greatly under differing conditions, and especially how the appearance changes with disease.

Urinary Deposits became a standard text on the subject; there were five editions between 1844 and 1857

Bird's Disease



Uric acid crystals drawn by Bird. On the left are crystals formed in normal urine; on the right, crystals from a patient suffering from kidney stones

Scope of the problem

Incidence- Primary Hyperoxaluria Type1 (commonest) – approximately one per every 1,20,000 live births

Prevalence- 10.5 for every million population (12,000 patients in India, where are they?!)

Oxalosis & Hyperoxaluria Foundation ohf.org

About the OHF

Since 1989, the OHF based in New York has raised & provided more than $10 million dollars for Primary Hyperoxaluria awareness & research

Today, the OHF serves as the most viable resource for patients, families, professionals and those affected by Primary Hyperoxaluria

K B Memorial Foundation

I believe Kanishka is watching from the other world and observing how his mother is going to materialize his wishes. He was a boy with full of wishes not for himself, but for mankind. He wished one day he will be a doctor and he will save small children, but his wish remain unfinished due to his early departure from this world. To fulfill the cherish idea of a great boy, as a mother I plan to build a foundation with the help of my father as well as with the help of my uncle who is also a renowned doctor, MRCP (Lond & Edin) encouraged me to keep our beloved son *'Kanishka's Life line on for years together'* through this **"Kanishka Binayak Memorial Foundation"** in my home town Midnapore. Actually, I got the spirit and inspiration from Kanishka's concern doctors and specially from Dr. Christopher J. Danpure , an Emeritus Professor of Molecular Cell Biology, United Kingdom while deliberating my talk " The Journey with my son " at 10th International Primary Hyperoxaluria workshop, Cologne, Germany, held on 22-23 June 2012.

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NRI REMEMBERS SON

Metabolic disorder centre in Midnapore

HT Correspondent
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KOLKATA: On July 28, Nibedita Saha, an NRI hailing from West Midnapore, will be living her son Kanishka Binayak Saha's unfulfilled dream, when she will inaugurate a support facility for patients of rare metabolic disorders, in his memory.

Kanishka died of primary hyperoxaluria type-I, a metabolic disorder, in 2011.

Kanishka went through a tough phase of repeated dialysis and transplants over two years that were of no help at the end and he died a painful death on May 19, 2011, at a hospital in Prague, with the unfulfilled dream of becoming a doctor and treat children of their fatal diseases. Now, his mother Nibedita has managed to rekindle his dream, with the establishment of 'Kanishka Binayak Memorial Foundation' in her hometown.

"We will be inaugurating the foundation on July 28 at the local zilla parishad hall. This is a step towards making Kanishka's name live even though he is no more here, it would also help his unfulfilled dreams come true to some extent," said Saha weeks prior to the inauguration, who is visiting India on this purpose.

File photo of Kanishka Saha with his parents. Kanishka had died of a metabolic disorder in 2011. HT PHOTO

Primary Hyperoxaluria, is an enzyme-linked metabolic disease that slowly starts affecting the excretory system in a person and results in complete renal failure. Even when Kanishka was detected with the disease by the Mayo Clinic, USA, doctors at Prague and Czech Republic, could not conclude a definite treatment procedure to bail him out.

He underwent combined transplant of both the kidneys and liver, yet he had to survive on dialysis for days after the transplant, which finally took away his life. "Kanishka himself asked me once, why did he need dialysis even after combined transplant of the kidney and liver. But we are yet to figure this out, as the doctors say, the disease is seen once in a million. This is why we are establishing this facility to help patients with similar symptoms in whatever way we can," said Saha who is a lecturer at the Tomas Bata University in Zlin, Czech Republic.

Her uncle, Dr BB Saha, who runs a diabetes clinic in the district, has helped Saha in establishing this facility. He said, "It will be a unit to help the suspected cases of metabolic disorders, with detection, advice and if proved, they would also be given some financial help. The district magistrate and CMOH would inaugurate the foundation on July 28."

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HINDUSTAN TIMES, KOLKATA
MONDAY, JULY 15, 2013

Kanishka sitting in a chair 8 days after his transplantation at IKEM, Prague

Indian Doctors give Life to 12 year Old Sudanese Boy

‘Domino’ for Primary Hyperoxaluria

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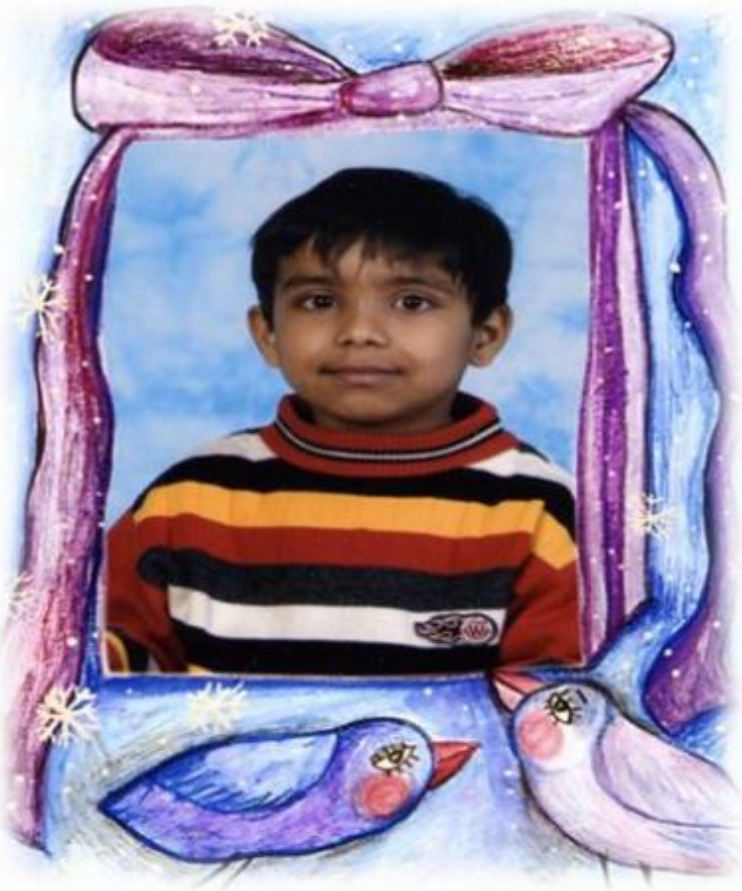
Mukhtar Ahmed Ali Gadkarim from Sudan had Primary Hyperoxaluria type1

Gadkarim got a liver and kidney, each one donated by two of his sisters in November 2012 in Delhi, operated by Dr Subhash Gupta and Dr Sandeep Guleria

Ms Arwa, 29, donated her kidney, Ms Asma, 27, donated her liver to save their youngest of four brothers. "Since he is our youngest brother, we could not see him suffer. We wanted him to live, so we got in touch with the doctors here through the internet," said Arwa

K B Memorial Foundation + ISOT = Primary Hyperoxaluria Society of India



ISOT

Indian Society of Organ Transplantation

The way forward for Primary Hyperoxaluria Society of India

Set up Website phf.org(?)

Set up a Society in coordination with ISOT

Raise funds

Yearly symposia at ISOT Conferences

KB Memorial Foundation

Collaborate with OHF

Hyperoxaluria Society of India

Proposed Mission

Supporting scientific research, which is dedicated to the understanding, discovery and development of potential new therapies while providing up to date information to industry and the public

Provide education, awareness, advocacy and national outreach by collaborating with partners to develop and expand resources, research and services


HOPE