



INTERNATIONAL
PATIENT ORGANISATION
FOR PRIMARY IMMUNODEFICIENCIES

FIRST GLOBAL LEADERS MEETING

www.ipopi.org



What is important in India?

Dr. Surjit Singh

Pediatric Allergy Immunology Unit,
Advanced Pediatrics Centre,
Post Graduate Institute of Medical Education and Research,
Chandigarh, India

Primary Immunodeficiency Disorders

Awareness

- Still considered to be exotic disorders about which one reads only in text-books
- Awareness amongst physicians / pediatricians

Primary Immunodeficiency Disorders

Diagnosis

Facilities for investigations

- Syndromic diagnosis
- Serum immunoglobulins and subclasses
- Lymphocyte subset analysis
- Molecular diagnosis – collaboration
with
(PGIMER, Chandigarh) Japan and France

Primary Immunodeficiency Disorders - I

Treatment

Bone marrow transplantation

- Severe combined immunodeficiency
- Wiskott-Aldrich syndrome
- Hyper-IgM syndrome

Bone marrow transplantation

- Christian Medical College, Vellore
- Tata Memorial Hospital, Mumbai
- Post Graduate Institute of Medical Education and Research, Chandigarh
- All India Institute of Medical Sciences, New Delhi

Primary Immunodeficiency Disorders - II

Treatment

Prophylactic antimicrobials

- Hyper-IgE syndrome
- Chronic granulomatous disease
- IgG subclass deficiency

Primary Immunodeficiency Disorders - III

Treatment

Intravenous immunoglobulin (IVIg) therapy

- X-linked agammaglobulinemia (XLA)
- Common variable immunodeficiency (CVID)
- Wiskott-Aldrich syndrome (WAS)
- IgG subclass deficiency

Primary Immunodeficiency Disorders - III

Treatment

- **IVIg therapy: problems**

	Prior to February 2008	After February 2008
Availability	Easy	Restricted
Cost per 5 grams	INR 2500 (= USD 50)	INR 9000 (= USD 180)

Indian Patients Society for Primary Immunodeficiency (IPSPI)

Success so far

- Registration
- Charity status
- Lobbying

Unresolved issues

- Branches in different states
- Manpower resources
- **Funding**

Cost of IVIg therapy as a proportion of parental income in India

Age of the child	Expected weight	Average monthly dose of	Cost of monthly IVIg	Cost of IVIg as a proportion of parental income*
1 year	10 kg.	5 grams	INR 9,000	18 %
5 years	20 kg.	10 grams	INR 18,000	36 %
10 years	30 kg.	15 grams	INR 27,000	54 %
15 years	50 kg.	25 grams	INR 45,000	90 %

***Average monthly income of a middle class household in India:
INR 50,000 (=USD 1000)**

How do patients / parents cope?

- Support of the joint family - ?
- Support of the employer - ?
- Health insurance - X

- **Philanthropists**
- **Non-governmental organizations (NGOs)**

How do patients / parents cope?

- **Undertreatment:** bronchiectasis, recurrent infections, hospitalizations
- **Interrupted treatment**

What is the way forward?

- Funding by the government:

issues involved

- Support of the pharmaceutical industry:

IVIg manufacturers

- Support of the industrial houses:

lobbying

Proposed National Hypogammaglobulinemia Treatment Facility

- Annual recurring costs USD 200,000
- Issues of funding?

