

# Campaign to Promote Awareness on PIDs among Community and Governors



**P**Primary immunodeficiency disorders (PIDs) are a heterogeneous group of inborn diseases due to incompetent development of various elements of immune system. The affected patients present several infectious and non-infectious manifestations constructing a constellation of signs and symptoms. A timely diagnosis and treatment would prevent persistent complications and reduce mortality and morbidity within these patients. Therefore, alongside the research, aiming at recognizing the nature of PIDs and introducing novel therapies, it is important to take these patients under appropriate treatment as soon as possible.

It has been shown that PID patients are often diagnosed with a substantial delay. It has also been demonstrated that shortage of awareness among family physicians and general practitioners contributes greatly to this delay. It is, thus, inevitable to increase the knowledge on PIDs among medical professionals. At the same time the community needs to be aware of these disorders for an on time medical consultation. In order to achieve aforementioned goals, the working groups and NGOs must convince the authorities, governmental bureaus and profitable organizations to sponsor programs and research in the field of Primary immunodeficiency disorders. This necessitates a comprehensive project to make needed materials available to target groups.

The Iranian Primary Immunodeficiency Association (IPIA) is to ignite such a program.

In this regard the IPIA made periodical meetings and reunions with authorities as consultants of related ministries, assembly members and other governmental organization as well as commercial units like pharmaceutical and biotech agents. This is an attempt to inform them about the importance of research and activity for patients with PIDs.

The IPIA is to develop a program to satisfy three major aims of its activities:

- 1- Increasing the understanding of PIDs among physicians, nurses, and families of patients
- 2- Introducing the concept of immunity and its primary defects in human to the general population.
- 3- Catching the attention of authorities to take the significance of PIDs into account when making health national policies.

The project would be accomplished in three steps:

## **STEP 1: NEED ASSESSMENT**

In this step we would try to evaluate the level of awareness about PIDS among different groups. This evaluation would be performed by means of questioners designed for this purpose.

- A- Need assessment among medical professionals as doctors and nurses by means of questioners.
- B- Need assessment among patients, their families and their
- C- Need assessment among general population.

## **STEP 2: PREPARING EDUCATIONAL PACKAGES**

Based on data coming out of former step, educational packages would be prepared for target groups. This consists of following materials:

### **A- BOOKS:**

Written by the expert and includes all topics of the PIDs:

- Antibody Deficiencies
- Cellular Immunity Defects
- Complement and Phagocytosis Defects
- Nursing of Patients with PIDs
- Simplified Concepts of Immunity and PIDs for General Readers
- Living with a Patient with PID for Patients and Families
- Log Book of Patients
- Self Assessment Pretest for Pediatric Residents

### **B- ATLASES:**

- Color Atlas of Primary Immunodeficiency Disorders
- Color Atlas of Skin Manifestations in PIDs

### **C- POSTERS:**

- Ten Warning Signs for PIDs.
- Approach to PIDs.

### **D- SLIDES**

Including all major topics on PIDs.

### **E- MEETINGS:**

- Continuous Medical Education Courses for General Physicians and Pediatricians
- Nursing Workshops
- Meeting with Patients and Families to Increase Their Understanding and Share Experiences

### **F- MOVIES:**

- Primary Immunodeficiency Disorders for Physicians
- Documentary for General Population

### **STEP3: AUTHORITIES**

#### **A-MEETING:**

Meeting with responsible divisions and commission in parliament and health ministry.

#### **B- OFFICIAL REPORTS:**

The official reports provided by the IPIA to health decision makers would help to envisage a quota of special fund for PIDs as providing additional insurance to patients.

#### **C: VIDEO:**

As many decision makers are not familiar directly with PID patients and their needs, producing documentary videos would give them a better impression of problems.