

# NIAID Primary Immune Deficiency Clinic

## What are primary immune deficiency diseases (PIDDs)?

PIDDs are caused by inherited defects in specific cells of the immune system. Currently, there are over 200 known PIDDs, and many more are yet to be identified. Individuals with PIDDs generally have an increased susceptibility to infections and may have other medical problems that include autoimmune diseases directed toward blood cells or endocrine organs such as the thyroid or pancreas, malabsorption with diarrhea, deteriorating lung function, tumors, and failure to thrive.

Approximately 500,000 Americans are diagnosed with PIDDs—5,000 to 10,000 of those with severe disease—but experts estimate approximately 500,000 more remain undiagnosed. Although each is relatively rare, a PIDD may be chronic and debilitating, often resulting in considerable pain and suffering, numerous hospitalizations, high medical costs, and, sometimes, premature death.

## What is the NIAID Primary Immune Deficiency (PID) Clinic?

The National Institute of Allergy and Infectious Diseases (NIAID) PID Clinic provides comprehensive consultations for individuals and their families affected by

PIDDs. The NIAID PID Clinic is a gateway for people affected by PIDDs. Those suspected of having a PIDD are welcome to have their medical records evaluated to determine whether they will benefit from coming to the NIAID PID Clinic for a thorough examination, diagnostic work up, and detailed list of recommendations that will be shared with the referring physician.

## Where is the NIAID PID Clinic located?

The NIAID PID Clinic is located at the Clinical Center on the National Institutes of Health (NIH) campus in Bethesda, MD.

## Who heads the NIAID PID Clinic?

The clinic is co-directed by Drs. Alexandra Freeman and Sergio Rosenzweig. Dr. Freeman is a physician in the Laboratory of Clinical Infectious Diseases (LCID). Dr. Rosenzweig is also the co-director of the Diagnostic Imaging Laboratory in the Department of Laboratory Medicine, NIH Clinical Center. Physicians and scientists from NIAID and NIH laboratories are also engaged in the PID Clinic.

Under the guidance of Drs. Freeman and Rosenzweig, NIAID clinical trainees in their second year also have



Left to right: Gulbu Uzel, M.D., Laboratory of Clinical Infectious Diseases (LCID); Jonathan Lyons, M.D., Laboratory of Allergic Diseases (LAD); Helen Matthews, R.N., Laboratory of Host Defenses (LHD) and Laboratory of Immunology (LI); Harry Malech, M.D., Chief, LHD; Morgan Similuk, Sc.M., C.G.C., LI; Thomas Fleisher, M.D., Chief, Department of Laboratory Medicine, NIH Clinical Center; Steven Holland, M.D., Chief, LCID; Sergio Rosenzweig, M.D., Ph.D., Co-Director; Alexandra Freeman, M.D., Co-Director; Joshua Milner, M.D., LAD; Anahita Agharahimi, M.S.N., C.R.N.P., LCID; Mary Garofalo, R.N., LHD; LCDR Ashleigh Hussey, B.S.M., R.N., NIAID



the opportunity to work with patients who come to the PID Clinic. In addition, the NIAID clinicians consult with local, national, and international experts in all fields of immune deficiency and immunology to assist patients who come to the NIAID PID Clinic.

### **How do I know if I am eligible to come to the NIAID PID Clinic?**

The PID Clinic accepts patients from 2 years old onward who have a known or suspected PIDD. People who have a PIDD but who have not previously been diagnosed usually suffer from recurrent, unusual, or difficult-to-treat infections.

If you are interested in coming to the clinic, discuss this option with your personal physician or specialist.

You must be referred to the NIAID PID Clinic by a physician, who will need to provide the following information about you:

- A summary letter describing your condition, when it was first observed, and your current health status
- A list of treatments and medications that you have taken in the past and their effects
- Copies of your complete medical records and any diagnostic tests such as MRIs, CT scans, and biopsies

Our clinicians will review your records and then decide if you would benefit from coming to the NIAID PID Clinic.

### **What will a visit to the NIAID PID Clinic involve?**

You and your referring physician will be notified if your case is accepted, and you will be invited to come to the NIAID PID Clinic at the NIH Clinical Center. There is no charge for your visit; however, your travel expenses will not be covered during this first visit.

The evaluation you receive will take at least one full day, and possibly two, depending on whether additional testing or consultation is required. Prior to your visit, NIAID clinicians specializing in immune deficiency diseases will review your medical history and consult with your referring physician. Consultation with your referring physician will be important throughout the process and for your follow up care.

Once you have been examined and, in some cases, after you have received a diagnosis from the NIAID PID Clinic staff, you will be given detailed information on treatment recommendations. You also may be offered the opportunity to participate in cutting-edge medical research in an NIAID clinical trial. Alternatively, you may be informed of PIDD studies for which you may be eligible at clinical centers outside of NIAID.

If you do come to the NIAID PID Clinic, our staff is committed to helping you manage your disease.

### **Where can I get more information?**

If you have further questions about the NIAID PID Clinic, please contact one of the following staff members:

- **Anahita Agharahimi, M.S.N., CRNP**, Nurse Practitioner for PID Clinic, 301-443-9817, [agharahimia@niaid.nih.gov](mailto:agharahimia@niaid.nih.gov)
- **Ashleigh Hussey, R.N., B.S.N., LT**, U.S. Public Health Service, Case Manager for PID Clinic, [husseya@niaid.nih.gov](mailto:husseya@niaid.nih.gov)
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- **Mary Garofalo, R.N., B.S.N.**, Research Nurse for LHD, 301-827-9758, [mgarofalo@niaid.nih.gov](mailto:mgarofalo@niaid.nih.gov)

More information about NIAID can be found at [www.niaid.nih.gov/about/organization/dir](http://www.niaid.nih.gov/about/organization/dir).



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