The Immune Deficiency Foundation (IDF) is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.
Welcome!

Dear IDF Volunteer,

Welcome to the Immune Deficiency Foundation’s Volunteer Network! You have joined an amazing organization that has established an outstanding reputation for providing accurate information, support and resources to individuals and families living with primary immunodeficiency diseases (PI). It is our hope that your volunteer experience will be rewarding and enjoyable.

Volunteering has been at the heart of IDF since it was founded. IDF volunteers are viewed as valuable resources to the PI community and part of the IDF team. It is through our wonderful volunteers that IDF reaches into hearts and communities throughout the nation.

We anticipate that your volunteer experience will provide you with new friendships, opportunities for personal growth and the satisfaction that comes from helping others in the PI community.

Thank you for choosing to volunteer for IDF. We extend to you our personal best wishes for your success and happiness as an IDF Volunteer.

Sincerely,

Marcia Boyle
President & Founder
# Table of Contents

About the Immune Deficiency Foundation ........................................................................ 4

IDF Volunteer Network ..................................................................................................... 5

Volunteer Opportunities .................................................................................................... 5

- IDF Liaison
- IDF Get Connected Leader
- Peer Support Coach
- IDF Friends Moderator
- Health Access Advocate
- Walk Planning Team
- Plasma Center Visitor

Requirements ...................................................................................................................... 6

What You Can Expect from IDF .......................................................................................... 6

What IDF Expects from You ............................................................................................... 6

Volunteer Training Opportunities ........................................................................................ 7

Volunteer Guidelines .......................................................................................................... 7

---

For general Information about the IDF Volunteer Network, contact IDF:

[volunteer@primaryimmune.org](mailto:volunteer@primaryimmune.org)

800-296-4433
About the Immune Deficiency Foundation

Mission Statement
The Immune Deficiency Foundation is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

Primary immunodeficiency diseases (PI) are a group of more than 250 rare, chronic disorders in which part of the body’s immune system is missing or functions improperly. Because one of the most important functions of the normal immune system is to protect us against infection, patients with PI commonly have an increased vulnerability to infections, which can be recurrent, unusually severe, or won’t clear up. People with PI can face frequent health problems and often develop serious and debilitating illnesses.

While not contagious, these diseases are caused by hereditary or genetic defects. Although some disorders present at birth or in early childhood, the disorders can affect anyone, regardless of age or gender. Some affect a single part of the immune system; others may affect one or more components of the system. And while the diseases may differ, they all share one common feature: each results from a defect in one of the functions of the body’s normal immune system.

Years ago, a diagnosis of a PI meant extremely compromised lives, not just for the patients but for their families as well. Today, with early diagnosis and appropriate therapies, many patients diagnosed with a PI can live healthy, productive lives.

Founded in 1980, the Immune Deficiency Foundation (IDF) is the national non-profit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with PI through advocacy, education and research. There are approximately 250,000 people who are diagnosed with PI in the U.S., and thousands more go undetected.

Individuals affected by PI often find it difficult to receive proper diagnosis, treatment and specialized healthcare. IDF estimates that the average length of time between onset of symptoms and diagnosis is between nine and 15 years. Patients also experience difficulties financing their healthcare, finding educational materials on the disease and locating others with whom to share their experiences. IDF helps individuals overcome these difficulties.

IDF provides accurate and timely information for patients and families living with PI and offers valuable resources. IDF…

- Helps the patient and medical community gain a broader understanding of PI through education and outreach efforts;
- Promotes, participates in, and conducts research that has helped characterize PI and given patients and physicians substantially improved treatment options;
- Addresses patient needs through public policy programs by focusing on issues such as insurance reimbursement, patient confidentiality, ensuring the safety and availability of immunoglobulin therapy, and maintaining and enhancing patient access to treatment options.

IDF does not charge patients or healthcare professionals for the educational materials or local programming that it provides. This is possible because of the generosity of the donors and sponsors who make gifts to IDF.

Thousands of individuals and families affected by PI depend on IDF for advocacy, education and empowerment.
IDF Volunteer Network

The Immune Deficiency Foundation (IDF) has a nationwide network of dedicated volunteers committed to making a difference by supporting the mission of IDF. Some volunteers increase awareness of primary immunodeficiency diseases (PI), while others offer encouragement and understanding to those who live with PI. Some help organize a Walk for PI in their town while another may prefer to advocate for public policy. Maybe you have a special skill or interest that will benefit our community—there is a place for you in the IDF Volunteer Network.

Whatever your interests or skills, we have an opportunity for you! Your time is valuable, so there are flexible options for even the busiest people.

Your Remarkable Impact

Volunteers contribute to the overall mission of IDF by providing another layer of support, compassion and skill to our team. As an IDF volunteer, you will have many opportunities to enrich the lives of others by sharing your time and talents. It is because of the passion and dedication of our volunteers that IDF is able to assist so many people throughout the country. Volunteers are truly at the heart of what we do.

Volunteer Service to IDF

Service as an IDF volunteer will begin with an official notice from the IDF Volunteer Development Manager or staff member overseeing the program. Active volunteers will be invited to renew their commitment on a yearly basis.

The mission and goals of IDF are national in scope. While individuals, families, health professionals and medical institutions across the country benefit from IDF’s programs and services, IDF evaluates its programs against national standards rather than individual or local needs. Therefore, it is vital that all local and regional activities led by volunteers are consistent with the mission and goals of IDF as a national organization.

Volunteer Status with IDF

IDF accepts the service of volunteers with the understanding that this service is at the discretion of the Foundation. Volunteers agree that IDF may decide to terminate the volunteer’s relationship with IDF at any time, for reasons such as failure to comply with any of the volunteer guidelines or conduct that is not in the best interest of the Foundation.

Similarly, the volunteer may at any time, for whatever reason, decide to end the volunteer’s relationship with IDF. Notice of such a decision should be communicated as soon as possible to the IDF Volunteer Development Manager.
Volunteer Opportunities

At IDF the possibilities are endless! Creativity and imagination, mixed with initiative and a caring heart, can make the volunteer experience memorable for everyone. Feel free to share with us how you think you can help. Below are some opportunities of volunteer roles that you can fulfill for IDF:

**IDF Liaison - Join the Movement to Spread Awareness in Your Community**
Be a part of our movement to educate and support IDF’s mission. IDF Liaisons assist us in a variety of ways, from reaching out to healthcare professionals and the public to representing IDF at health fairs and community events.

**IDF Get Connected Leader - Make Connections in the PI Community**
Serve as a support group leader and give the gift of friendship, information and resources. You can help plan and organize regular support group meetings in your local area for people with PI and their family members.

**Peer Support Coach – Support Individuals in the PI Community**
Getting help from someone who has walked in your shoes can make a huge difference in living with PI. We are seeking volunteers who can provide a listening ear both online and one-on-one for individuals living with PI and their family members. The shared experiences that the Peer Support Coaches offer demonstrates that they are not alone.

**IDF Friends Moderator – Get Involved in IDF’s Online Community**
This is an exciting opportunity for anyone who wishes to be actively engaged in this exceptional online community. We are seeking volunteers to help provide a welcoming and safe environment on IDF Friends, IDF’s social network for patients and families living with primary immunodeficiencies: www.idffriends.org.

**Health Access Advocate – Make a Difference through Advocacy**
Make change happen by reaching out to government officials. Volunteers will work with IDF staff to advocate in their areas. If you like the idea of scheduling meetings with legislators and/or community leaders to educate them about state and federal legislative issues related to PI, then this is the volunteer role for you!

**Walk Planning Team – Lend a Hand to IDF Walk for PI**
Be a part of an IDF Walk for PI Planning Team near you! Planning Team members work with IDF staff on various areas of planning, including: team formation, team management, logistical support, outreach to the medical community and event day activities. Join in and help to raise awareness about PI!

**Plasma Center Visitor – Motivate Others to Support the PI Community**
By sharing your personal story, volunteers help put a “face” to the work that we do at IDF. Plasma Center Visitors represent others in the PI community to express their gratitude to donors for their contributions. If you are comfortable with occasionally talking to small or large groups of people at plasma centers about how their support helps to save lives, then contact us today!
Requirements

We’ve compiled this handbook to help you have a rewarding experience as a volunteer, and reviewing the information we have here is the first step.

Universal Volunteer Requirements

- Visit the IDF Volunteer Connection Center and create a volunteer profile.
- Review the IDF Volunteer Handbook.
- Complete the online IDF Volunteer Orientation.

Depending upon which volunteer position you choose, you have a few more steps to take:

Additional Requirements – Based on the Volunteer Position May Include:

- Successfully complete a criminal background check, if age 18 or over.*
- If requested, references, writing samples, portfolios, professional certifications or other requirements may be needed depending on the position.*

* Position descriptions will list additional requirements.

What You Can Expect from IDF

IDF will:

- Provide information and support to help you carry out your volunteer duties.
- Keep your information confidential.
- Provide prompt attention to any concerns that may arise.
- Make sure your individual rights are respected and that all volunteers are treated with courtesy and consideration.
- Conduct communications and all business in a spirit of friendliness and cooperation.

What IDF Expects from You as a Volunteer

You will:

- Act in a professional manner and cooperate with fellow volunteers, medical professionals and the public while representing IDF.
- Perform every task to the very best of your ability while focusing on the mission of IDF.
- Keep IDF informed of activities you are doing in your area.
- Discuss any problem or ask any question to any member of the IDF staff. We encourage you to contribute your suggestions to improve the quality of IDF’s programs.
- Take advantage of opportunities for personal development offered to you by IDF.
Volunteer Training Opportunities

Regardless of the volunteer opportunity you choose, IDF is going to provide you with support and training in one or more of the following ways.

- How-to guides or information provided via email
- Online training modules to be completed during a time that works for your schedule
- Conference calls
- One-to-one calls
- On-site trainings prior to an event
- Training seminars

IDF Volunteer Connection Center

Our volunteers are a valuable resource to the PI community. When you’re ready to get involved, simply select the opportunity that matches your interest to get started. The IDF Volunteer Connection Center has several features and allows each volunteer to have their own unique profile. Through the IDF Volunteer Connection Center, IDF volunteers will be able to:

- search for available volunteer opportunities and view details about each role
- easily apply/sign-up for volunteer positions that match their interests
- view opportunities that they have applied for or been assigned to
- view completed trainings
- submit/track their volunteer service hours
- submit volunteer service reports to their IDF staff contact

Volunteer Guidelines

Attendance & Participation

IDF encourages volunteers to take care of themselves and their families before fulfilling their volunteer duties. We understand that there are times when volunteers may be unable to carry out their duties and may need to become inactive due to illness or other situations. This is understandable and respected by the Foundation.

In situations where a volunteer expects that they will be inactive for a significant amount of time, information should be communicated to the IDF Volunteer Development Manager as soon as possible. IDF supports volunteers who want to take a break and will be happy to welcome them back at a later date.

Please understand that a great deal of time, resources and finances go into the projects, events and activities offered by IDF. In an effort to develop and maintain quality volunteer opportunities, it is important that volunteers are present and on time for their scheduled service activities. Additionally, please do not sign up for a volunteer opportunity if you cannot commit to the time requirement.

If you are not able to fulfill an assignment, please contact the appropriate IDF staff person as soon as possible. If you cannot get in touch with the individual, please contact the IDF Volunteer Development Manager.
Confidentiality

While serving as a volunteer, confidential information may be available to you, including the names and contact information of individuals and family members in the PI community. Just as you would want your information protected, you should take all appropriate steps to maintain the confidentiality of such information and use it only for purposes related to IDF activities and not for personal or business activities.

We are entrusting you with the responsibility to protect against unauthorized, inappropriate, or illegal disclosure or use of such information during and after volunteering with IDF. We take this matter extremely seriously, and violations of this policy will result in termination from the volunteer program and could lead to legal action.

Tips to Protect Confidentiality:

- **E-mail:** When sending e-mails to more than one individual, simply blind carbon copy (Bcc) the recipients, so their names and email addresses are not visible to others. Recipients will appreciate the effort you take to do this.

- **Online Discussion/Support Groups:** IDF Friends, [www.idffriends.org](http://www.idffriends.org), the social network developed by IDF specifically for individuals living with PI, is the perfect place for the PI community to connect. However, this community is exclusive to patients and family members, so we ask that you only refer individuals with PI and their family members to IDF Friends.

- **Industry Partners:** We ask that you do not share the names/contact information of individuals with PI, their family members or volunteers with representatives of companies that provide a product or service to the PI Community.

- **Database:** Mailing lists for IDF events will only be available to IDF staff. IDF staff will use their database to complete all mailings for IDF events and meetings. Volunteers are responsible for updating IDF with contact information received from individuals in the PI community with their permission. You should not create and maintain a mailing list separate from IDF. Updated information should be given to your IDF staff contact.

Criminal History

IDF will not accept a volunteer who has a criminal history or engages in criminal activity which indicates behaviors potentially harmful to individuals, documented through either a criminal history records check, a criminal background check or through other information. Any volunteer of IDF shall report promptly to the IDF Volunteer Development Manager when the volunteer has been accused of any criminal activity. IDF has sole discretion to determine whether information obtained through the background check process disqualifies an individual from serving as a volunteer with the Foundation.

Drugs & Alcohol

*Drug Use*

Prescription and over the counter medications are permissible if used according to the directions and do not interfere with the volunteer’s duties and responsibilities. Volunteers must notify IDF within five days of any convictions for drug violations.

*Alcohol Use*

At IDF events where alcohol is served, moderate consumption of alcoholic beverages is permitted. As a representative of the IDF Volunteer Network, volunteers who choose to drink alcoholic beverages are expected to behave in a professional manner and adhere to the volunteer policies. Additionally:

- Alcohol is to be restricted to areas designed for consumption of food and drink. **Food must be available for guests.**
- Self-serving of alcoholic beverages at agency functions is prohibited.
Alcohol is not to be served to minors or anyone who appears to be impaired.
Safe passage home must be arranged for anyone who appears to be impaired.

**Equal Volunteering Opportunity**

IDF provides equal volunteering opportunity for everyone regardless of age, gender, color, race, creed, national origin, religion, marital status, political belief, sexual orientation or disability that does not prohibit performance of essential volunteer duties. All matters relating to volunteering are based upon ability to perform the job, as well as dependability and reliability.

**Expense Reimbursement**

In some cases, an IDF volunteer incurs expenses while conducting business on behalf of the Foundation. Volunteers are expected to ensure that such expenditures are appropriate, that adequate cost control measures are in place, and that reimbursement for authorized expenses is made in a timely manner.

Volunteers will only be reimbursed for pre-approved expenses, such as snacks for Get Connected Meetings — items should not be purchased until approval is given. All expense reimbursements are on a case by case basis. Expense reimbursements are offered to volunteers on a case by case basis and should be discussed with your IDF staff contact to determine if your purchase is eligible for reimbursement.

Please note that IDF does not cover the expense of purchasing alcohol.

**Financial Policies**

To ensure that IDF meets IRS requirements and maintains consistent financial bookkeeping and reporting standards, the subsequent guidelines and policies must be followed.

- Prior to planning an event, please contact IDF.
- All receipts and records must accompany pre-approved expenses.
- All monies raised by the Foundation and its volunteers are the property of the Foundation and will be used towards accomplishing the mission of IDF.
- Contingent upon IDF approval, volunteers may engage in joint fundraisers with other nonprofit organizations provided the fundraisers meet the goals of the Foundation.
- Volunteers cannot sign binding contracts for IDF.

**Harassment**

As a part of our commitment to equal opportunity, IDF has adopted an anti-harassment policy. Any volunteer who engages in harassment based on race, color, religion, national origin, sex, gender, sexual orientation, marital status, disability, age, or other legally protected characteristics, is guilty of misconduct.

Examples of harassment may include derogatory comments regarding a person’s race, color, religion, or other protected characteristics, sexually explicit or other offensive images (whether printed or displayed on a computer), and jokes that are based on stereotypes.

IDF volunteers are responsible for keeping our volunteer network free of harassment. A volunteer, who becomes aware of an incident of harassment, whether by witnessing the incident or being told of it, must report it to any IDF staff person with whom you feel comfortable.
Interaction with Industry Partners - Companies Providing a Product or Service to the PI Community

IDF has specific standards for how its volunteers should interact with representatives from industry partners (manufacturers, specialty pharmacies, homecare providers, and other medical product companies) providing a product or service to the PI community. To maintain our impartiality, we ask that all volunteers adhere to the following guidelines:

- Contact with the national corporate offices of industry partners should be made by the IDF office only, unless other arrangements have been approved.
- IDF volunteers should not solicit industry partners for funds or items for local events.
- Volunteers receiving an offer of support from an industry partner should contact the IDF Vice President of Education & Volunteer Development immediately for further direction.
- It is inappropriate for industry partners to attend the Person-to-Person Discussion Session at an IDF Education Meeting or attend IDF Get Connected Groups. These groups are designed for individuals and family members who live with PI only.
- Industry partners may not collect names/contact information of attendees at IDF events.
- Volunteers should never share names/contact information of individuals and family members in the PI community with industry partners.
- The Foundation neither endorses nor censures a specific company, product, healthcare professional or service. IDF and its volunteers must remain separate from any appearance of endorsement or censure.

Maintaining Boundaries

Your service to IDF will lead to many opportunities to network with a variety of different people in the PI community. It is crucial that volunteers do not blur the lines between their volunteer service to IDF and the groups that they will have contact with through IDF.

Tips to Maintain Appropriate Boundaries:

- Solicitation: Don’t solicit anyone in the PI community to participate in surveys developed by companies providing a product or service for PI, outside survey agencies or to support a business where you will gain financially.
- Publications: All IDF publications are approved by the Medical Advisory Committee. For this reason, please only distribute IDF developed materials. It is inappropriate for IDF volunteers to distribute materials created by companies providing a product or service to the PI community. Volunteer designed materials must be approved by IDF.
- Meetings/events: It is inappropriate for IDF volunteers to coordinate or help coordinate events for companies providing a product or service to the PI community or to invite patients or family members met through IDF to these events.
Medical Advice

IDF volunteers should never provide medical advice or opinions regarding diagnosis or the treatment of PI.

Individuals seeking medical advice should be referred to their physician. If an individual does not have a specialist, IDF can help locate one in their area.

Volunteers should never speak in a derogatory manner regarding a medical professional.

Unusual Occurrences/Non-Emergency

To protect the rights, health and safety of everyone IDF serves, all volunteers are expected to report any unusual occurrences during an IDF event or activity within 24 hours to the IDF Volunteer Development Manager. Unusual occurrences include but are not limited to hospitalization, injury, theft, calling 911 or any incident that has an impact on the health or safety of the individuals served by IDF. If a volunteer is injured while actively volunteering at an IDF event or activity, they must report it immediately to the IDF Volunteer Development Manager. An Incident Form must be completed by the volunteer.

Violence

Violence, or threats of violence, by a volunteer or against anyone else will not be tolerated. If a volunteer receives or overhears any threatening communications or observes physical or verbal confrontation at an IDF sponsored event, the volunteer must report it to IDF staff immediately. Additionally, no volunteer should engage in either a physical or verbal confrontation with anyone.

No IDF volunteer shall bring any gun or weapons to any Foundation sponsored event or activity or onto any other property where the volunteer is representing IDF.

Volunteer Grievances

Misunderstandings or conflicts can arise. Volunteer grievances are of concern to IDF, regardless of whether problems are large or small. To ensure effective working relations, it is important that such matters be resolved before serious problems develop. Most incidents resolve themselves naturally. However, if a situation persists that a volunteer believes is detrimental to themselves or to IDF, they should speak to IDF Volunteer Development Management about the appropriate steps.

Working with the Media

Volunteers must seek guidance from IDF when providing information to the media in their official roles as volunteers. Only volunteers who have prior approval should speak to the media on IDF’s behalf. If you do not and you are contacted by a reporter or blogger, please let them know that IDF will be pleased to respond, but the reporter/media contact must first contact the IDF Communications Department, which coordinates media contacts.
Stay Updated

It is important to stay updated regarding issues in the IDF community.

- Subscribe to IDF Blog updates: www.primaryimmune.org/blog
- Sign up for IDF Action Alerts:
  - www.primaryimmune.org/idf-advocacy-center/action-alerts/action-alerts-sign-up
- Like IDF on Facebook:
  - www.facebook.com/ImmuneDeficiencyFoundation
  - www.facebook.com/WalkForPI
- Follow IDF on Twitter: www.twitter.com/IDFCommunity
- Follow IDF on Instagram: www.instagram.com/idfcommunity
- Review IDF materials and become familiar with content
- Attend national and local IDF meetings and conferences