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.

*IDF Get Connected Groups are part of the IDF Outreach Initiative, which is sponsored by Baxalta US Inc.*
Welcome!

Thank you for choosing to become an IDF Get Connected Leader for the Immune Deficiency Foundation (IDF)! We appreciate your willingness to share your time, talents and enthusiasm with individuals and family members living with primary immunodeficiency diseases (PI), and we look forward to how you will positively impact the community.

Sometimes individuals and family members simply want to talk with someone who understands what it’s like to live with PI. They find value in actually meeting others in person, learning the latest about PI and connecting about much more than their diagnosis. The IDF Outreach Initiative encourages individuals living with PI to get together in their local areas through IDF Get Connected Groups.

These groups are in-person networking opportunities designed to bring together individuals from the PI community in their local area. Leaders facilitate a welcoming environment conducive to sharing ideas and support, so that participants feel a sense of belonging to the IDF community, assuring them that they are not alone.

Serving as a Get Connected Leaders will help fulfill the mission of IDF—to improve the diagnosis, treatment and quality of life of persons with PI through advocacy, education and research. Your work will not only help promote awareness of PI but also knowledge of the valuable resources IDF provides. To reach more individuals and families, we need a nationwide effort from dedicated people like you. In addition to the work of IDF staff, we must develop and cultivate strong partnerships with individuals with PI, caregivers, healthcare professionals and local community leaders. Volunteers play a critical role in this effort and serve our community in a variety of ways, from advocacy to fundraising, to outreach and more.

As an IDF Get Connected Leader, you are an important member of the IDF team. You can provide comfort to individuals and families living with PI. Over the years, IDF Get Connected Groups have grown and become a tremendous resource for people who want to connect with others and to know they are not alone. Your role as an IDF Get Connected Leader is to support, encourage and unite individuals in their local areas by giving them support and creating a sense of belonging with others in the PI community.

This training guide will prepare you to have the best possible experience as a volunteer. It provides answers to frequently asked questions, gives information about facilitating an IDF Get Connected Group and describes your role as the group’s leader. If you have questions, contact IDF at volunteer@primaryimmune.org or 800-296-4433.

We are happy to have you as part of the team—our work together can help many individuals and families living with PI and seeking support.
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What Is an IDF Get Connected Group?

IDF Get Connected Groups are designed to connect individuals diagnosed with primary immunodeficiency diseases (PI) and family members in their local communities. The meetings can occur at a local community room, library, coffee shop, church or other cost-free venue. Through IDF Get Connected Groups, individuals and families connect to share experiences, receive information and gain support. These groups do not include presentations or industry exhibits.

Get Connected Groups typically range between three to 15 attendees. An IDF Get Connected Leader, with the input from group members, selects a discussion topic and leads a conversation between the group members. Participants express opinions and gain information on the topic and learn from the other group participants.

Group discussion is an effective way to:

- Create support between participants
- Share ideas and broaden viewpoints
- Stimulate interest about a topic or issue
- Help participants express their ideas
- Create an informal atmosphere

IDF Get Connected Leader Responsibilities

Key Responsibilities:

- Represent IDF in your local community by hosting an IDF Get Connected Group at least two times per year.
- Locate an accessible venue for the group to meet.
- Convene the first group and support the group on its way to a being a local support community for each other.
- Plan useful discussions.
- Make people feel welcome and comfortable.
- Keep participants in touch with each other in-between meetings through social media, especially IDF Friends, www.idffriends.org, the social network developed by IDF specifically for individuals living with PI.
- Represent IDF and meet the needs of the participants in the group.
- Join the IDF Get Connected Leaders group on IDF Friends.
- Regularly communicate with IDF staff and report group activity.
- Make sure you have a private email account (not shared with another person, spouse, etc.) or create one that can be used for your IDF Volunteer responsibilities.
Who can attend an IDF Get Connected Group?

Individuals diagnosed with PI and family members who are not employed by a company providing a product or service to the PI community are invited to attend IDF Get Connected Meetings.

Support & Training from IDF

Support:

- The Program Manager will be your primary contact.
- IDF staff will:
  - Create and send invitations.
  - Collect RSVPs.
  - Ship materials and paperwork to you at least one week prior to each group.
  - E-mail a list of attendees to you at least 24 hours before the group.
  - Reimburse you for refreshments provided to the group. (Additional information is available on page 19 of this guide.)

Training (required):

- The following training is required:
  - IDF Volunteer Orientation
  - IDF Get Connected Leader Training

Note: This training is self-paced and completed in your own home.

Basic Leadership Skills

In general, there are some basic skills that can help you lead any type of group:

- **Be creative**: Many attendees come to a group for the first time with the mindset that they will only attend once. Think of creative ways to engage these people so they will return.
- **Be energetic**: Your energy may be the tipping point that gets people engaged. If you show little or no enthusiasm, everyone else may follow suit. If you are enthusiastic, the good energy will catch on!
- **Be positive**: Believe that the attendees can learn something new to help them in their journey.
- **Be patient**: Don’t get discouraged if it seems like attendees aren’t participating. Always remember that one or more participants of the group are benefiting from your support.
**Tips for Leading an IDF Get Connected Group**

Within this section, we have included some tips for leading a successful group. Keep in mind that IDF is an organization with many resources for individuals in the PI community, and you are the person who can tell others about those resources! Your primary responsibility as an IDF Get Connected Leader is to provide attendees with support from caring people who understand what they have been going through and to connect them with the appropriate IDF resources.

Here are some basic rules to having a successful Get Connected Group:

- **Start on time and end on time.** Delaying the meeting start time for the sake of late-comers only penalizes those that do make the effort to show up promptly.

- **Introduce guests.** This starts the group on a friendly tone and helps people feel more comfortable.

- **Prepare and follow an agenda.** Agendas are critical to the success of the group—we can’t stress this enough! While we want to give everyone a chance to speak when appropriate, set agendas help keep control of time.

- **Create a congenial atmosphere.** Attendees gain the most when they are comfortable and at ease. They need opportunities to get to know each other, talk together and build trust. A few ideas to help create a positive atmosphere are team-building activities or ice breaker activities. See page 13 of this guide for ice breaker activities.

- **Choose interesting discussion topics.** Stay informed about the issues that are affecting everyone in the PI community. This can help generate participation and keep people coming back! Use the resources that are available on the IDF website, [www.primaryimmune.org](http://www.primaryimmune.org), page 11 of this publication, or contact IDF to help you identify things that can be discussed.

- **Empower the attendees.** Encourage participants to be active within the group during and after the meeting. Creating a group on IDF Friends, [www.idffriends.org](http://www.idffriends.org), is a great way to stay connected. Through IDF Friends, invite others to learn about future meetings and receive input from others regarding future topics and provide support, which will help everyone feel more empowered.
Tools for Leading Successful Meetings

A little preparation goes a long way! Planning and preparing for the group will help you have a successful meeting. The following tips will help encourage informative and helpful discussions.

How Can I Lead a Productive IDF Get Connected Group?

- Keep the discussion on track. If the discussion gets side-tracked, bring it back to the main subject by suggesting more important points that need to be covered in the time allotted.

- Clarify statements when necessary to assure general understanding. For example, periodically stop to review important points that have been made.

- Model appropriate behavior for attendees.

- Remind attendees of the “Golden Rule.” Nothing that is shared should be discussed outside of the group.

- Seating arrangements are very important. Arrange chairs so that people can make eye contact. A circle, semicircle, U-shaped or hollow square work well.

- Call on individuals who seem ready to talk rather than going around in a circle. Allow individuals the opportunity to pass or simply listen to others.

- Participate as an equal peer, direct rather than dominate the discussion and ease yourself into the background when the group gets started.

- Don’t allow anyone to monopolize the discussion. Interrupt them tactfully, and lead the discussion to another person. Suggestions for managing challenging participants are included on pages 15-16 of this guide.

- If you think an important point is being neglected, mention it.

- Keep spirits high and encourage ease and informality. Let everyone have a good time and don’t let the discussion become dull.

- At the conclusion of the group, quickly summarize the important facts in the discussion.

What Should I Be Careful to Avoid?

- Steer clear of participants overtly injecting personal opinions or values.

- Discourage any attendees, including yourself, suggestion to try a particular course of treatment, medication, physician, or take a certain course of action.

- Remember, this is not a “therapy session.”

- Prevent any negative discussion or comments about a healthcare provider.
Let’s Get Started

Organizing an IDF Get Connected Group requires coordinating with the IDF office. The following timeline is provided to enable everyone to understand the process involved.

3 - 6 months before the Get Connected Group

- Contact IDF at volunteer@primaryimmune.org with your interest in convening an IDF Get Connected Group in your area.
- Select an easily accessible venue for your group. Space is often available at your local library, school, college, community center, medical facility or coffee shop. Information to help you select a venue is available on page 9 of this guide.
- If the venue requires a contract, contact IDF. Volunteers cannot sign binding contracts for IDF.

4 - 6 weeks before the Get Connected Group

- The IDF national office will create and send invitations.
- IDF staff will accept RSVPs and send the list of attendees to the volunteer prior to the meeting. The list will be used to check off attendees as they arrive and returned to IDF after the group meeting.

Note: The list of attendees is confidential. Only IDF staff or group leaders can have access to it.

1 - 2 weeks before the Get Connected Group

- IDF will send any necessary forms and literature to you.

The week of the Get Connected Group

- Registration typically stays open until three (3) days prior to the meeting. The confirmed registration list will be sent via e-mail to you once registration has closed.

1 week after the Get Connected Group

- Return the following to IDF:
  - List of attendees noting who attended and who did not
  - IDF Get Connected Group Follow Up Report
  - IDF Contact Forms
  - Evaluations
  - IDF Volunteer Expense Reimbursement Form
Things to Consider When Selecting a Venue

- The venue must be free.
- Verify room availability.
- Are tables and chairs provided?
- Will the tables and chairs be set up for you?
- How many people will the room hold, considering if some are in wheelchairs?
- How many steps are involved - inside and outside? Is there an elevator?
- Is the parking safe and convenient? Is there a good “drop-off” place near the meeting room?
- Is the entire building including restrooms, accessible to walkers and wheelchairs?
- Are the restrooms located near the meeting room and on the same floor?
- Is the room adequately heated and/or air-conditioned?
- How will you gain access to the building especially on nights and weekends?
- Will staff be available?
- Who is the contact person, and how can they be contacted?
- Is liability insurance required? (Many facilities have their own.)
- Is the facility able to help your group advertise its presence?
IDF Get Connected Group Procedure

Registration

- Check attendees off the list as they arrive.
- Distribute the following information.
  - IDF Contact Form
  - IDF Get Connected Group Agenda
  - Evaluation

Agenda

- Welcome everyone!
- Share the following information with the attendees.
  - IDF Get Connected Groups are part of the IDF Outreach Initiative, which is sponsored by Baxalta US Inc. – be sure to acknowledge at each meeting that refreshments are supported by Baxalta. A Welcome sign with acknowledgement is included on page 27 and will be sent to you to display at all meetings.
  - IDF is a great resource for patients and families. (Mention the website & IDF Friends). IDF provides peer support & will help with school issues or insurance issues.
  - Briefly show IDF publications or share new information. Program Manager will update leaders when new information is available.

Please ask new attendees to complete the IDF Contact Form and give it to you. You will send these to IDF. IDF staff and volunteers will not share personal information with anyone.

- IDF Get Connected Groups provide a time to network and meet others. Review the following group rules.
  - Everything stays confidential not to be discussed outside of the room.
  - Only one person speaks at a time.
  - What every person says is valid. We are here to support each other.
  - Give everyone a chance to speak.
  - Negative comments about medical professionals are not allowed.
  - The final word on anything regarding anyone’s treatment comes from their physician.

Guidelines for Participants

The following guidelines will help participants contribute effectively to the group:

- Be an active part of the group.
- Work to solve common issues and discuss topics of interest.
- Discuss completely, but do not argue.
- Contribute ideas related to the subject of the discussion.
- Ask questions to clarify ideas.
- Be clear and brief.
- Listen and learn.
- Take note of useful ideas.
- Group Introductions:
  - What is your name? Why are you here?
  - Announce the group topic for this meeting. (Everyone speaks once or has the option to pass.) Select a topic from the following list or ask IDF for suggestions. Please share your ideas with IDF so they will be shared with other volunteers. If there is extra time, please allow an open discussion within the group.
Closing

- Stay involved – does the group want to continue to meet?
  - Set/brainstorm a place.
  - Set/brainstorm a date and time.
  - Who will help?
  - Plan to communicate through IDF Friends.
  - Do you want to share contact information with each other?
- Thank everyone for attending.
  - Collect the attendee list, IDF Contact Forms, evaluations & other materials. Return these forms to IDF via e-mail, postal mail or fax.

Possible Discussion Topics

Each IDF Get Connected Group should feature a discussion topic. Possible discussion topics submitted by volunteers are listed below. If you need help selecting a topic or you have suggestions for additional topics, contact IDF.

Discussion Topics
Be Your Own Healthcare Advocate
Caring for the Caregiver
Communicating with Your Child’s School
Communicating with Your Healthcare Team
Coordinating Your Care between Specialists
Coping with an Invisible Disorder
Creating a Support System
Explaining PI to Family & Friends
Handling Emergencies
Health Insurance*
IDF Resources for You & Your Family
Living Life to the Fullest with PI
Make a Difference in the PI Community
Pacing Yourself during the Holiday Season
Parenting a Child Diagnosed with PI
PI in the Workplace
Picnic or Holiday Get-together
Public Policy & Advocacy Issues in the PI Community*
Stress Management & Relaxation Tips
Telling Your Story & Creating Awareness about PI
Traveling with PI

*An Expert Guest Discussion Leader from Baxalta is available for this topic.
Planning Ahead: Creating a Calendar

Please plan on coordinating at least two IDF Get Connected Groups within a calendar year. The number of meetings depends on local weather patterns, the preferences of the participants and other IDF events that may be taking place in your area. Many groups avoid difficult winter months, or especially “slow” summer months. In any event, these are not the best months to schedule meetings for your group.

Of course, each group’s calendar will be different. The general idea is to have several educational topics with at least a few information discussions scheduled in between. One or two social or public awareness activities should fit naturally at certain times of the year. It is a good idea to publish your calendar in advance to help participants plan ahead with their spouses or other family members.

Below is an example of a calendar for monthly meetings:

**January**
Kick off the New Year by Being Your Own Healthcare Advocate

**February**
Living Life to the Fullest with PI

**March**
Make a Difference in the PI Community

**April – National Primary Immunodeficiency Awareness Month and World PI Week**
Explaining PI to Family & Friends

**May**
Summer Travel Tips

**June**
Parenting a Child Diagnosed with PI & the Child Who Doesn’t Have PI

**July**
Family Picnic Day

**August**
Communicating with Your Child’s School

**September**
Creating a Support System

**October**
Pacing Yourself during the Holiday Season

**November**
Living Life to the Fullest with PI

**December**
Holiday Get-together
Why Icebreakers?

Icebreakers can play an important role in helping people connect with one another in a group environment. Icebreakers can also enhance your facilitation skills by helping to stimulate cooperation and participation. They can provide positive momentum for small group discussions by:

- Helping a new group get to know one another.
- Helping new members integrate into the group.
- Encouraging cooperation and working together.
- Listening to others.
- Developing social skills.
- Building a rapport with leaders.
- Creating a good atmosphere for learning and participation.

A 10 Second Checklist

- Be enthusiastic.
- If something is not working, move quickly to the next activity.
- Timing is important. Use only 1 or 2 icebreakers as a 10-15 minute introduction to your program. Finish each icebreaker while people are still enjoying it.
- Choose appropriate icebreakers. Each group is different, and your understanding of what will and will not work with your group is a core skill.

Icebreaker Activities

- **Serious Sam & Inquiring Ida**
  Ask each participant to choose an adjective that begins with the first letter of their first name and one that really matches their personality and write it on a card. Have them introduce themselves just as they wrote it on the card and allow time for others to ask questions.

- **Dream Vacation**
  Ask participants to introduce themselves and describe details of their dream vacation.

- **Birthday Partner**
  Have participants mingle in the group and identify the person whose birthdate (not year - just month and date) is closest to their own. Find out two things they have in common.

- **The Five of Anything Ice Breaker**
  You can use any number for this fun ice breaker that quickly allows participants to share interests. Make the interests germane to your session or let your participants learn more about each other. This ice breaker is easily customized to your group’s needs.

- **10 Things in Common**
  In this ice breaker, find 10 things that you have in common with the other participants in your group. You start by telling them that simple cop-outs such as body parts are not allowed.
Supporting Others as an IDF Get Connected Leader

Sensitivity Can Go a Long Way
Leaders should be sensitive to the people who attend a Get Connected Group. Always be aware if someone:

- is hurting
- needs more time to talk
- is made uncomfortable by excessive talk on a certain subject
- is uncomfortable with the attitudes or actions of others in the group
- needs a chance to talk one-on-one to someone
- is in critical need of professional help
- is suicidal or in crisis

Some suggestions to say to someone struggling with depression are:

1. You're right, this is tough.
People who are depressed don't want problem solvers — they've usually run through all the scenarios and solutions in their head already. What they're looking for is acknowledgement and empathy.

2. You don't walk this path alone. I'm here if you need me.
When a person is depressed, one of the feelings many people experience is an overwhelming sense of loneliness — that no one can understand what they're going through. A reminder from a friend or loved one that, indeed, they're not alone and they are loved can be invaluable. It also reminds them of the reality — that people in their life do love them and are there for them if they need them.

3. I believe in you... You're awesome!
Sometimes a person has given up hope that they'll amount to anything in life. They've lost all belief in themselves and feel like nothing they do is right or good enough. Their self-esteem is gone. That's why it can be helpful to reaffirm that you believe in them. You believe in their ability to once again experience hope, to be the person you once were — or even more if they're not feeling that way at the moment.

4. How can I help? What can I do for you?
One way many people experience depression is that they have little motivation to do things that need to get done. Offer your support and direct assistance in getting something done for them. It might be picking up a prescription, groceries from the store or simply getting the mail. Offer this help only if you're willing to do what is asked of you.

5. I'm here for you.
Choose something you know the friend or loved one is going to be interested in doing. Maybe they just want to talk (and need you to simply listen). Maybe they need a nudge to get up, get changed and just do something. You can be that person to help them get moving.

6. I know it's hard to see this right now, but it's only temporary... Things will change. You won't feel this way forever. Look to that day.
When a person's depressed, sometimes they lose all perspective. Depression can feel like an endless black hole in which there's no way out. Saying something along these lines reminds them that all of our emotions and moods are not permanent, even if they feel like they are. More than anything, take the time to listen and get to know the people who attend the IDF Get Connected Group. Having someone who cares, means more than you know. You can always call the IDF Program Manager or Volunteer Development Manager if you find an individual or situation to be overwhelming.
Sometimes a situation can be more serious. For examples of suicide warning signs, you can refer to www.suicidepreventionlifeline.org/learn/warningsigns. The National Suicide Prevention Lifeline, www.suicidepreventionlifeline.org, provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week. Their phone number is 1-800-273-TALK (8255). Calls are routed to the Lifeline Center closest to the caller’s area code. The organization also has information regarding how to help someone who talks about suicide via social media: www.suicidepreventionlifeline.org/gethelp/online.

Managing Challenging Participants

The following information is provided to familiarize you with some challenging behaviors of participants and suggestions regarding how to intervene and keep the group on track.

Side-Talkers
Holding side conversations is defined as having conversations or continually whispering to others during a discussion or presentation. At the beginning of the meeting discuss ground rules for a respectful listening and talking environment. Remind everyone of the rules if necessary.

Disputers
Disputing the information presented, questioning material endlessly and disputing solid information with anecdotal evidence is a characteristic of a disputer. Critical thinking is always welcome, but this behavior is disruptive and not productive. Using words like “maybe” “perhaps” or “I wonder if”; or using “we” or “us” stead of “I” or “you” helps to keep disputers on track.

Know-It-Alls
Dominating the discussion with an “I know everything” attitude is a common place for the Know-It-All. This behavior can inhibit others from speaking up during discussion. Listen politely, but do not be afraid to get back on topic. Set the stage for everyone’s input. Restate the person’s ideas, and use questions to get ideas from others in the group.

Ramblers
Rambling on and on occurs when an individual tells a story or raises an issue in a long-winded, irrelevant manner. Others in the group may disengage, daydream, chat with their neighbor or basically tune out. The group could select a person to serve as “timer” whenever group discussion occurs. This person can use a simple hand signal or yield sign as a soundless reminder that time is up.

Attackers
Attackers thrive on arguing. They look for an opportunity to disagree or pick at an idea, make personal attacks and don’t let go of their own idea to hear others. This could also include someone who is constantly commenting about other’s ideas in a critical or unkind manner, blaming others or showing hostility. If you can, change this person’s focus and try to acknowledge the positive points of their argument as a cue to move on.

Silent Types
These participants can usually be found acting indifferent or passive, not being involved in the discussion, occupying themselves by doodling or whispering to others, getting off the subject or displaying a lack of self-confidence. Try getting the participant to share ideas in advance, and give them credit as positive reinforcement for their contribution.

Whiners
These participants are continuously finding fault, blaming, complaining that things are unfair, always expressing dissatisfaction with the way things are or discouraging anything new or different. Focus on the discussion, and if applicable ask the person to offer a replacement idea.
Clowns
The attention seeking participant likes to clown around and disrupt the group’s efforts to come to a conclusion or calls attention to self. To assist with staying on task, restate the purpose of the discussion so that the goals are clear to everyone.

Managing Challenging Participants

<table>
<thead>
<tr>
<th>The Challenger</th>
<th>The participant might say…</th>
<th>You might reply…</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side-Talkers</td>
<td>There is constant chatter going on in the back of the room.</td>
<td>&quot;I am having a difficult time listening when there are side conversations going on.”</td>
</tr>
<tr>
<td>Disputers</td>
<td>“That’s not quite accurate. My doctor told me something else about that treatment.” “I read online about that therapy, it is not at all effective.”</td>
<td>&quot;I see where you are coming from but…” or ‘I appreciate your perspective. However…”</td>
</tr>
<tr>
<td>Ramblers</td>
<td>Someone is rambling on-and-on about an issue they are having with his/her insurance carrier.</td>
<td>&quot;Wow, that’s a dilemma, but we can’t solve that one now. Could you and I talk about this afterwards?”</td>
</tr>
<tr>
<td>Attackers</td>
<td>“Any mother that uses that treatment is just asking for things to get worse!”</td>
<td>&quot;I see you have strong opinions. Let’s hear what the others think.”</td>
</tr>
<tr>
<td>Know-It-Alls</td>
<td>&quot;I was diagnosed 20 years ago and I’ve been through it all. What you need to do is try alternative medicines.”</td>
<td>&quot;That is an interesting perspective, but let's get back to the question at hand&quot; OR &quot;I'd be interested in where you got that information. Would you share that with me later?”</td>
</tr>
<tr>
<td>Whiners</td>
<td>“I told them what they should do, but they didn’t want to listen to me.” OR “We tried that once, and it didn't work.”</td>
<td>&quot;That can be frustrating, but we do have to remember that every situation is different, and there are lots of factors to consider.”</td>
</tr>
<tr>
<td>Clowns</td>
<td>The participant is constantly making joking remarks when information is being presented.</td>
<td>Smile at the comment and say “True, but in all seriousness, can we discuss our thoughts on this issue?”</td>
</tr>
<tr>
<td>Silent Types</td>
<td>A participant doesn’t contribute to any of the conversations, even when he/she seems to react to the discussion around him/her.</td>
<td>At the next meeting, engage the participant before the discussion begins, you may even have him/her help you with a task that will cause him/her to interact with others.</td>
</tr>
</tbody>
</table>
Group Cancellation Procedure

There are times when an unavoidable circumstance will cause you to cancel an IDF Get Connected Group. Make the decision as soon as possible to cancel the meeting so that attendees can be notified.

If you need to cancel an IDF Get Connected Group due to a personal emergency or inclement weather:

- Contact the IDF Program Manager with the date and location of the meeting and your contact information. If applicable, offer a date that the meeting can be rescheduled, check to make sure the location is available and give this information to the IDF Program Manager.
- Contact the venue and ask if they could post a sign on the door the day of the meeting was supposed to be held, in case someone did not get the notice.
- Contact the registered attendees or ask the IDF Program Manager to contact the attendees.

Keeping Attendance Up

Even the most upbeat IDF Get Connected Group can have its “down” times. This may be due to any number of factors, including:

- A lapse in meetings due to weather, availability of meeting space or turnover in leadership
- You’ve had multiple absences or are no longer able to lead the group due to illness, work or life’s demands.
- A decline in the number of attendees due to illness, work or life’s demands.

What should you do?
First, know that is okay for the group to take a break. Those who live with PI are familiar with that piece of wisdom. After taking a break, many groups come back stronger and with renewed participants.

Whether you choose to take a break or not, the following ideas may help your group to rejuvenate:

- Contact a missing participant and invite them back. If they cannot attend, offer to support them via phone or e-mail. Ask if they would like you to share a message with the group.
- Organize a fun get-together, such as a picnic, holiday party or lunch.
- Talk to other IDF Get Connected Leaders.
- Ask IDF staff for help.

Of course, none of these suggestions can neither make everything right nor restore your group to the way it was. Change is a reality in the life of every group, just as it is in the lives of every individual. Allow your group to change and acknowledge the down times to encourage the group to talk about them. Finally, don’t be afraid to take a break and re-group.
IDF Get Connected Group Leader Support & Staying Connected

IDF Get Connected Groups have successfully operated throughout the country for several years. Leaders should join the private **IDF Get Connected Group Leaders Group** on IDF Friends, www.idffriends.org. This group enables leaders to meet others and share ideas. **IDF Friends** is also where leaders can create a discussion for their local members to stay in touch between meetings.

**Steps for Joining the IDF Get Connected Group Leaders Private Group**

1. After creating your IDF Friends account or logging in, please click on the “Groups” button at the top of the screen or visit www.idffriends.org/groups.

2. Locate the IDF Get Connected Group Leaders group and click on “Request Membership”.

3. Approval is necessary for this group because it is private. If you experience any problems joining this group or have any questions about IDF Friends, please contact us here: www.idffriends.org/contact-us/

In order for participants in your IDF Get Connected Group to discuss via IDF Friends, please create your specific discussion for your local members to stay in touch between meetings. Below are instructions to create your topic discussion.

**Steps for Creating a Discussion Topic for your Get Connected Group:**

1. When logged in to IDF Friends, click the Groups link at the top of the screen and search for IDF Get Connected Groups or go directly to: http://idffriends.org/groups/idf-get-connected-groups/ and click Join.

2. Once you are in the group, click on “Forum”. This is where you want to create your specific discussion group.

3. Where it says “Topic Title” type in your Get Connected Discussion Group. For example:

   - **Get Connected Group – Houston, TX** – You can use the specific city for other members to identify which group this is.

4. Next, add in a brief description in the body of the topic. For example:

   - Welcome to the IDF Get Connected Group for those in the Houston, TX area. Please feel free to comment here and share your thoughts, ask questions and get feedback from others in your community.

5. Click "Submit."

6. Your discussion is now created. This is public, so those in IDF Friends can join in the conversation. Please copy the link specific to your discussion topic and send to your members to join in the conversation.

7. For any questions or concerns, please contact us via www.idffriends.org/contact-us/.
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.

- Volunteers must contact IDF prior to planning any event to benefit the organization.
- Volunteers should not solicit or accept money for personal use or for any individual family or medical institution.
- All monies raised by IDF and its volunteers is property of IDF and will be used toward accomplishing the mission.
- Contingent upon IDF approval, volunteers may engage in joint fundraisers with other nonprofit organizations provided the fundraisers meet the goals of IDF.
- Volunteers cannot sign binding contracts for IDF.

Expense Reimbursement

As an IDF Get Connected Leader, you may incur expenses while conducting business on behalf of IDF. 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. Items should not be purchased until approval is given.*

- When hosting an event, IDF does NOT cover the expense of purchasing alcohol.
- We recommend bringing refreshments to your groups. Examples of approved items include:
  - Snacks – chips, cookies, granola bars, fruit, etc.
  - Beverages – soda, water, coffee, iced tea
- The IDF Program Manager will discuss refreshment ideas and cost guidelines with you prior to your event, based on your group location and number of attendees.

Report expenses accurately and in a timely manner by completing and submitting an IDF Volunteer Expense Reimbursement Form. This report should be submitted to your IDF staff supervisor within five days of the completion of the meeting. Original receipts or legible copies must be attached and submitted with the expense reimbursement form.

IDF cannot guarantee a reimbursement for purchases that are not previously approved or submitted incorrectly.

The IDF Volunteer Expense Reimbursement Form, which is on the next page, should be used to submit expenses for reimbursement.
IDF Volunteer Expense Reimbursement Form

All requests for reimbursement must be received within five (5) days from the date that the activity/event is held and must be accompanied with ORIGINAL, SCANNED OR PHOTOCOPIED ITEMIZED RECEIPTS. Failure to follow this procedure may result in disallowance of the request. Send this form to your IDF staff supervisor. A check will be issued within 14 days of approval. Please allow reasonable time for mail delivery.

Volunteer First Name  Volunteer Last Name

Street Address  City  State  Zip

Day Phone  Evening phone  E-mail address

Activity/Event Name: ___________________________ Date: __________

NOTE: In order to be reimbursed, you must receive prior authorization from your IDF staff supervisor for all expenses. Receipts for all items must accompany this form.

<table>
<thead>
<tr>
<th>Date</th>
<th>Item Purchased</th>
<th>Description/Purpose</th>
<th>Amount</th>
<th>GL #</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

Total to be Reimbursed $ ______

I hereby certify that the above is a true and correct statement of expenses incurred by me in the service of IDF.

Volunteer Signature: ____________________________________________ Date: __________

FOR IDF USE ONLY

Department  Project Code

Approved by: ______________________________________  Signature  Date

Immune Deficiency Foundation
Attn: Volunteer Network
110 West Road, Suite 300
Towson, MD 21204
410-321-6647 or 800-296-4433
Fax: 410-321-9165
www.primaryimmune.org
IDF Get Connected Group Follow-Up Report

Thank you for leading an IDF Get Connected Group! Please complete the following checklist and information and return to IDF. If you prefer to send an e-mail, please include this information. The main purpose of this report is to ensure IDF receives the required items and your feedback—we appreciate your timely assistance with this!

- Fax, scan & e-mail, or send a copy of your completed sign in sheet.
- Fax, scan & e-mail, or send a copy of any IDF Contact Forms completed by new attendees or those who need to update their information.
- Fax, scan & e-mail, or send a copy of all completed IDF Get Connected Group Evaluations/Volunteer Forms.

Comments regarding your Get Connected Group:

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

Next date your group plans to meet: ________________________________

Items you need replenished/sent out to you: ________________________________

Please return this form via e-mail, fax or postal mail to:

Immune Deficiency Foundation  
ATTN: IDF Volunteer Network  
110 West Road, Suite 300  
Towson, MD 21204  
Fax: 877-396-4525  
E-mail: volunteer@primaryimmune.org
INVITATION #1
(Meeting at a medical facility for parents of children & teens diagnosed with PI)

IDF Get Connected Group
A Networking Opportunity for Parents of Children & Teens Diagnosed with a Primary Immunodeficiency

Saturday, July 25, 2015
10:00 AM – 12:00 PM
The Health Resource Center at Children’s Hospital
123 First Street
North City, IN 01234

Discussion Topic: Communicating with Your Healthcare Providers

IDF Get Connected Groups provide an opportunity for individuals diagnosed with a primary immunodeficiency disease and family members to network in their local community.

There is no cost to attend. Refreshments will be provided.

Reservations are required. Please register by Wednesday, July 22.
Online:  www.primaryimmune.org/events-calendar/
E-mail:  idfmeetings@primaryimmune.org
Phone:  800-296-4433

Please note: This group is only open to individuals diagnosed with a primary immunodeficiency disease and family members who do not provide a product or service to the PI community.

IDF Get Connected Groups are part of the IDF Outreach Initiative, which is sponsored by Baxalta US Inc.

The Immune Deficiency Foundation (IDF) Get Connected Group offers an opportunity for individuals and family members to network with each other. The views and opinions expressed by group members do not necessarily reflect the views and opinions of IDF. The information discussed during the Get Connected Group is not medical advice, nor is it intended to be a substitute for medical advice, diagnosis or treatment. Always seek the advice of a physician or other qualified health provider with questions concerning a medical condition. Never disregard professional medical advice, or delay seeking it based on information discussed during the Group.
**SAMPLE**
INVITATION #2
(Meeting at a restaurant for individuals with PI & family members)

IDF Get Connected Group
A Networking Opportunity for Individuals
Diagnosed with Primary Immunodeficiency Diseases
& Family Members

Saturday, July 25, 2015
1:00 – 3:00 PM
The Annex Cafe
123 Main Street
South City, TN 12345

Discussion Topic: Living Life to the Fullest with PI

IDF Get Connected Groups provide an opportunity for individuals diagnosed with a primary immunodeficiency disease and family members to network in their local community.

There is no cost to attend. Refreshments will be provided.

Reservations are required. Please register by Wednesday, July 22.

Online: www.primaryimmune.org/events-calendar/
E-mail: idfmeetings@primaryimmune.org
Phone: 800-296-4433

Please note: This group is only open to individuals diagnosed with a primary immunodeficiency disease and family members who do not provide a product or service to the PI community.

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**SAMPLE**

IDF Get Connected Group Evaluation

City, State

Date

Thank you for your feedback. It will assist IDF in planning future programs.

<table>
<thead>
<tr>
<th>Introductory Activity</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Didn't Attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>I enjoyed this session.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Discussion Session</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Didn't Attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>I learned information that will be helpful to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I shared information with others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I enjoyed this session.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I am attending as a(n) _____ Individual with PI _____ Parent _____ Spouse/Partner/Friend

<table>
<thead>
<tr>
<th>Have you ever attended an IDF event in the past?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would recommend this event to others.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How did you hear about this event?

_____ I received an invitation from IDF via postal mail or e-mail.

_____ IDF Website

_____ IDF Friends

_____ The following individual or organization told me about this event.__________________________

What was the most valuable part of this event for you? __________________________________________

________________________________________________________________________________________

Comments & Suggestions for Future Topics: ______________________________________________________

________________________________________________________________________________________

_IDF Get Connected Groups are part of the IDF Outreach Initiative, which is sponsored by Baxalta US Inc._

**Make a difference in the PI Community… Volunteer for IDF!**

Additional information is available on the other side, page 2.
Please select all areas of interest.

Nationwide, On-going Volunteer Roles:

- **IDF Liaisons** will build relationships with healthcare providers who care for individuals diagnosed with PI or who may not be familiar with PI and provide them with IDF resources and information.

- **IDF Get Connected Leaders** will support, encourage and unite individuals in their local areas by planning and organizing regular in-person networking opportunities for people living with PI and their family members.

- **IDF Friends Moderators** provide a welcoming and safe environment for individuals living with PI and family members at IDF Friends, our online community, by welcoming new members, contributing to discussions and posting messages.

- **IDF Peer Support Coaches** provide one-to-one support via email or phone as the need arises to individuals with PI and family members.

- **Health Access Advocates** schedule meetings with legislators and/or community leaders to educate them about state and federal legislative issues related to PI.

Regional, As Needed Volunteer Roles:

- **IDF Event Facilitators** help at state-level education events by greeting attendees, introducing presenters, taking photographs or leading a person-to-person session.

- **IDF Plasma Center Visitors** are individuals with PI currently receiving Ig therapy or an immediate family member. They speak to groups of staff and donors about their lifesaving commitment to the PI community.

**Walk for PI**

- **Committee Member** – Apply to join an IDF Walk for PI committee if there is one in your city.

- **Community Walk Program** – There is not a Walk in my city. Please send me information about this program.

**Other**

- **Undecided** – Please contact me, and help me decide how I can get involved.

- **I am currently an active IDF volunteer.**

**Special Training**

I have training in an area that might be helpful to IDF.

- **Education/Teaching**
- **Employment Issues**
- **Health Insurance**
- **Mental Health**

- **Other Expertise/Talents:** ________________________________________________________________

**Highest Degree Obtained**

________________________________________________________________________________________

Briefly explain how you would like to use your training to benefit IDF.

_____________________________________________________________________________________

_____________________________________________________________________________________

**Please contact me about the volunteer opportunities marked above.**

**Name:** ______________________________________________________________

**E-mail:** __________________________________________ **Phone:** ______________________ (Day__ Evening__)

**City:** ______________________________________________ **State:** __________

IDF Get Connected Leader GUIDE - 25
**SAMPLE** IDF CONTACT FORM
For Individuals and Families

### Patient Information (One Patient per Form)

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient's Last Name</td>
<td>First:</td>
</tr>
<tr>
<td>Birth year</td>
<td>Gender:</td>
</tr>
<tr>
<td>Year of Diagnosis:</td>
<td>Middle:</td>
</tr>
<tr>
<td>Street address:</td>
<td>Suffix:</td>
</tr>
<tr>
<td>City</td>
<td>State:</td>
</tr>
<tr>
<td>Home Phone:</td>
<td>ZIP Code:</td>
</tr>
<tr>
<td>Mobile Phone:</td>
<td>Home Phone:</td>
</tr>
<tr>
<td>Email</td>
<td>Mobile Phone:</td>
</tr>
</tbody>
</table>

### Current Diagnosis

- [ ] __Agammaglobulinemia (XLA)__
- [ ] __Ataxia Telangiectasia__
- [ ] __Chronic Granulomatous Disease__
- [ ] __Common Variable Immunodeficiency__
- [ ] __Complement Deficiency__
- [ ] __DiGeorge Anomaly__
- [ ] __Hereditary Angiodema__
- [ ] __Hyper IgM Syndrome__
- [ ] __Hypogammaglobulinemia__
- [ ] __IgG Subclass Deficiency__
- [ ] __Selective IgA Deficiency__
- [ ] __Severe Combined Immunodeficiency__
- [ ] __Severe Congenital Neutropenia__
- [ ] __Specific Antibody Deficiency__
- [ ] __Wiskott-Aldrich Syndrome__
- [ ] __Not sure__
- [ ] __Other (please specify):__

### Physician Treating for Primary Immunodeficiency

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>City and State:</td>
</tr>
</tbody>
</table>

### Current Primary Health Insurance (Select one)

- [ ] __Employer Coverage__
- [ ] __Individual Policy__
- [ ] __Medicaid__
- [ ] __Medicare__
- [ ] __Uninsured__
- [ ] __Other (please specify):__

### Current Treatments (Select all that apply)

- [ ] __Intravenous Immunoglobulin (IVIG)__
- [ ] __Subcutaneous Immunoglobulin (SCIG)__
- [ ] __Intramuscular Immunoglobulin (IM)__
- [ ] __Hyaluronidase-Facilitated Subcutaneous Infusion Immunoglobulin (HY SCIG)__
- [ ] __Gamma Interferon__
- [ ] __PEG-ADA__
- [ ] __Prophylactic Antibiotic Therapy__
- [ ] __Other:______________________________

### Parent/Caregiver Information (If patient is under 18)

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last Name</td>
<td>First:</td>
</tr>
<tr>
<td>Street address</td>
<td>Middle:</td>
</tr>
<tr>
<td>City</td>
<td>Suffix:</td>
</tr>
<tr>
<td>City</td>
<td>State:</td>
</tr>
<tr>
<td>Home Phone:</td>
<td>ZIP Code:</td>
</tr>
<tr>
<td>Mobile Phone:</td>
<td>Home Phone:</td>
</tr>
<tr>
<td>Email</td>
<td>Mobile Phone:</td>
</tr>
<tr>
<td>Relationship to Patient:</td>
<td><strong>Parent/Caregiver</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Spouse/Partner</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Sibling</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Other (please specify):</strong></td>
</tr>
</tbody>
</table>

### How Did You Hear about IDF?

- [ ] __Internet search__
- [ ] __Healthcare Professional__
- [ ] __Other Patient/Family Member__
- [ ] __IDF Materials__
- [ ] __Newspaper Article/News Story__
- [ ] __Company providing a product or service to the PI Community__
- [ ] __Other______________________________

IDF Get Connected Leader GUIDE - 26
**SAMPLE**

ATTENDEE LIST / SIGN-IN SHEET
*Get Connected Leader, please check off who attends and add anyone to the list that is not registered. Be sure to have any new attendees fill out an IDF CONTACT FORM, so we can add them to our Database and keep them informed of future events!

IDF Get Connected Group
Your City, ST
Saturday, January 1, 2016

<table>
<thead>
<tr>
<th>Last Name</th>
<th>First Name</th>
<th># Attending</th>
<th>New to IDF?</th>
<th>Parent or Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zebra</td>
<td>Zippy</td>
<td>1</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>LION</td>
<td>Lucy</td>
<td>2</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Giraffe</td>
<td>George</td>
<td>1</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Hippo</td>
<td>Henry</td>
<td>2</td>
<td>Yes</td>
<td>No</td>
</tr>
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<td></td>
<td></td>
<td>Total 6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

IDF Get Connected Groups are part of the IDF Outreach Initiative, which is sponsored by Baxalta US Inc.

Please note:
This page needs to be faxed, (410-321-9165) emailed (hjensen@primaryimmune.org) or sent back to IDF with your other paperwork within 5 days of your IDF Get Connected Group event. Thank you!
Welcome to Our IDF Get Connected Group

Refreshments are supported by Baxalta US Inc.
www.baxalta.com
IDF Contact Information

Immune Deficiency Foundation
110 West Road, Suite 300
Towson, Maryland 21204
800-296-4433
volunteer@primaryimmune.org