IWMF CONNECT PARTICIPATION RULES AND ETIQUETTE

1. **YOUR MESSAGES REFLECT UPON YOU AND MAY BE THE ONLY WAY SOME PEOPLE KNOW YOU**.
    Most people will only know you by what you say to the group and how well you say it. Take some time to make sure each message won't embarrass you now or later. Your message will remain in the message archives and could continue to haunt you in the future. Minimize your spelling errors and make sure that the message is easy to read and to understand.

2. **BE MINDFUL OF KEEPING TO THE FOCUS OF IWMF CONNECT (no political or religious discussions)**.
    Keep your messages related to WM, diagnosis, treatment, results, or tests. This also means NO politics, NO religion, etc. Abuse of this rule will result in your subscription being put on review and removal if it becomes necessary. However, this does not mean that one cannot offer to pray on another member's behalf. Usually, such a message is more of a private message meant for just that person; but, in situations where it is part of a much larger message to be shared with everyone, then mentioning prayer is appropriate. Praying for someone is not discussing religion – it is an offering of support. Just remember, discussing things like religion and politics inevitably leads to rancorous communications and flame wars and simply cannot be allowed.

3. **BE BRIEF.**
    Say what you have to say succinctly and it will have a greater impact. Remember that the longer you make your message, the less likely it is that people will bother to read it.

4. **USE DESCRIPTIVE SUBJECT LINES.**
    The subject line of a message enables people to decide whether or not to read your message. Tell people what the message is about before they read it. Don't expect people to read your message to find out what it's about – many won't bother. Some e-mail programs limit the length of the subject line that is visible, so keep your subjects short and to the point.

5. **OPTIONAL: YOU CAN USE A HASHTAG IF YOU WISH TO; IT'S NOT NECESSARY (HASHTAGS CAN HELP IDENTIFY THE FOCUS OF A MESSAGE).**
    Hashtags are meant to let other group members know in advance the general "topic" or "category" that your message fits into. They can help members decide whether to read more (or not) and can make searching through previous messages much easier. A complete list of hashtags can be found at: http://www.iwmf.com/get-support/iwmf-connect-and-online-discussion-forums. Remember, if you're not sure what hashtag to use, just use #General (for example, if you're participating via email, your SUBJECT could be #General Question About Antibiotics).

6. **WHEN CHANGING THE SUBJECT, CHANGE THE SUBJECT LINE.**
    Often, people will begin an email message by selecting a prior email message from the group and clicking the reply button on their email program. This results in a new message to the group, but the subject line from the prior message (and often the text of the prior message) is carried into the new message. If your intent instead was to change the subject, this is confusing to the message recipients and also interferes with the proper threading of the message in the message archive. Please make sure your subject line accurately reflects the content of your message. **Don't forget that if you're changing the subject, you may need to change the hashtag too!**

7. **BE CAREFUL WITH HUMOR AND SARCASM**.
    Without the benefit of voice inflection and body language, it is easy for remarks meant to be funny to be misinterpreted. Subtle humor can easily get lost, and the intended meaning of the message can be perceived to be something offensive through misinterpretation. Also, remember that the members of the list are all very busy. If the only point of a reply is to be humorous, refrain from sending it in the interest of not wasting the collective time of the group members.

8. **FOR "EMAIL ONLY USERS": WHEN REPLYING TO A MESSAGE, SUMMARIZE WHAT YOU ARE REPLYING TO.**
    "Email Only" users, when you reply to someone's message, summarize the parts of the message to which you are responding. This allows readers to quickly place your comments in context and eliminates the need for them to try to find the original message or remember what the original message said. The easiest way to summarize is to include the text of the original message, which most email programs will allow you to do automatically. However, if you are replying to a long message with multiple points, don't include the entire message. Take the time to edit the text of the original to retain the salient points to which you are responding and also keep your own email short. Nobody like having to re-read messages either. (We also will have storage limitations to consider on IWMF Connect.)

9. **DON'T REPEAT WHAT HAS ALREADY BEEN SAID IN OTHER REPLY MESSAGES.**

   Before you submit a reply to a message, read the rest of the messages sent to the group to see whether someone has already said what you want to say. If someone has, don't repeat it. This saves everyone's time. Also, unless a message is polling the group on some question, avoid sending replies that simply state "I agree" or "Me too." These responses do not advance the discussion and require each group member to review the message. Again, please refrain from such messages in the interest of not wasting the collective time of the group members.

10. **BE COURTEOUS AND PROFESSIONAL IN YOUR PARTICIPATION IN THE GROUP.**

    Don't forget that you are interacting with people, not a computer. Because your interaction with the group is through a computer, it is easy to forget that there are people on the other side of the messages and replies that you send. Don't attack people. Conduct a calm and reasoned discussion based on relevant facts. Cursing and abusive language is inappropriate. Such conduct causes a discussion to deteriorate and makes people less willing to help you when you need it. Repeated incidents of abusive conduct may also get you involuntarily removed from the group. Inappropriate personal attacks also reflect poorly on you and will remain in the message archives to haunt you. If you are upset at something or someone, wait until you have had a chance to calm down and think about it. Hasty, knee-jerk responses only serve to fan the flames. Take the time to formulate a well-reasoned response that places the discussion back on track.

11. **SIGNATURE/SIGN-OFF TAG GUIDELINES:**

    This is entirely optional (as some folks may not wish to share such information), but it would be of great help if, with each message we send, we append a signoff/signature that is something like what is presented below. For many, it is of great assistance in assessing the state of a fellow member's condition and comparing our own condition with those of others.
    Here's a template you may wish to utilize for your signature:

    Name
    Country-City
    Year of Birth; diagnosis date (Month, Year)
    Treatments: cycles, drugs, dates
    IgM at diagnosis, highest IgM and date, lowest IgM and date, current IgM and date

    For an example, see my signature tag below…

    Peter L. DeNardis (USA - Pittsburgh, PA) - IWMF Connect Manager
    born 1960, dx: Oct 2003
    tx#1: x2 Cladribine Jan-Feb 2004
    tx#2: (IgM: 5940 mg/dL) x6 Fludara, Cytoxan Dec 2004-Jul 2005, x4 Rituxan Dec 2004, x6 Rituxan Jan-Jul 2005
    tx#3: (IgM: 1600 mg/dL) - with LPL tumor and symptoms); Cytoxan/Rituxan Oct-Nov 2010 and radiation (for tumors)

    IgM at diagnosis: ???; highest 6570 mg/dL 01/2004; lowest and current: 75 mg/dl 05/2010

    Please feel free to contact us with questions about IWMF Connect or if you experience any problems. Our IWMF Connect contact is Pete DeNardis at pdenardis@gmail.com.

FOR "EMAIL ONLY" PARTICIPANTS: Tips to help handle the avalanche of messages that can clog your inbox:

1) Set up a folder to automatically collect all messages from IWMF Connect. This can be done within your e-mail software system. Check your "Help" file for instructions.
2) Another suggestion is to subscribe to one of the other Email Delivery options offered on IWMF Connect. One option will collect all messages from the group and send you one long collection every day. For instructions on how to choose this and other Email

Delivery options, see the "How to Manage Your IWMF Connect Subscription" at: http://www.iwmf.com/get-support/iwmf-connect-and-online-discussion-forums or contact Pete DeNardis at pdenardis@gmail.com.

3) Better yet, just go to https://groups.io/g/iwmfconnect, log in, and start communicating with everyone. You'll be glad you switched to using the online portal!