

IWMF CONNECT PARTICIPATION RULES AND ETIQUETTE

- 1. 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. 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.
- 2. BE COURTEOUS AND PROFESSIONAL IN YOUR PARTICIPATION IN THE GROUP.**

Be courteous at all times, and don't attack people. Conduct a calm and reasoned discussion based on relevant facts. Also, 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. 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 in a courteous manner.
- 3. 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 and come from a wide range of backgrounds, cultures, and countries. 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.
- 4. BE BRIEF.**
- 5. USE DESCRIPTIVE SUBJECT LINES.**
- 6. OPTIONAL: YOU CAN USE A HASHTAG IF YOU WISH TO; IT'S NOT NECESSARY (HASHTAGS CAN HELP IDENTIFY THE FOCUS OF A MESSAGE).**
- 7. WHEN CHANGING THE SUBJECT, CHANGE THE SUBJECT LINE.**
- 8. DON'T REPEAT WHAT HAS ALREADY BEEN SAID IN OTHER REPLY MESSAGES.**
- 9. 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.
- 10. 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) –

born 1960, dx: Oct 2003

tx#1: x2 Cladribine Jan-Feb 2004

tx#2: (IgM: 5940 mg/dL) x6 Fludara, Cytosan Dec 2004-Jul 2005, x4 Rituxan Dec 2004, x6 Rituxan Jan-Jul 2005

tx#3: (IgM: 1600 mg/dL) - with LPL tumor and symptoms); Cytosan/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 office@iwmf.com