

# ACMCRN Community Guidelines for Peer Support Meetings & Special Events

Arachnoiditis & Chronic Meningitis Collaborative Research Network (ACMCRN) is committed to providing welcoming, respectful, and supportive spaces for people impacted by Arachnoiditis and Chronic Meningitis, including patients, caregivers, family members, advocates, clinicians, and community partners.

By attending an ACMCRN Peer Support Meeting or Special Event, participants agree to help create an environment where everyone can participate safely and respectfully.

## Our Shared Expectations

Please treat one another with kindness, patience, and respect.

We welcome different experiences, perspectives, cultures, identities, stages of illness, and levels of participation. You are welcome to share, ask questions, listen quietly, keep your camera off, or leave early if needed.

To help protect this space:

- Speak from your own experience and avoid speaking for others.
- Respect each person's right to privacy, boundaries, and choices.
- Avoid interrupting, personal attacks, hostile language, harassment, discrimination, or inflammatory comments.
- Do not pressure anyone to share personal information, medical details, photographs, or contact information.
- Do not share another participant's story, name, image, health information, or comments outside the meeting without their explicit permission.
- Do not use meetings to promote products, services, fundraising campaigns, political causes, or personal businesses unless specifically approved by ACMCRN in advance.
- Please keep discussion relevant to the purpose of the meeting or event and follow guidance from the moderator or host.

ACMCRN reserves the right to address disruptive behavior, remove a participant, or limit future participation when needed to protect the safety and well-being of the community.

## Privacy and Confidentiality

Many people attending ACMCRN programs may share personal health experiences, difficult emotions, or sensitive information. Participants are expected to respect the confidentiality of what is shared.

Please do not repeat, post, quote, screenshot, photograph, record, or share another participant's comments or identifying information outside the meeting without clear permission from that individual.

Participants should avoid sharing private information about other people, including names, medical details, contact information, or photographs, unless they have permission to do so.

## **ACMCRN Peer Support Meetings: No Recording Policy**

To protect the privacy of participants, **ACMCRN Peer Support Meetings are never recorded.**

This includes:

- No audio recording
- No video recording
- No screen recording
- No screenshots or photographs
- No livestreaming
- No transcription services
- No AI meeting assistants, bots, note-taking tools, or automated summaries
- No designated note-takers

ACMCRN will not record Peer Support Meetings, and participants may not record, transcribe, screenshot, or otherwise capture any part of these meetings.

Please do not copy or share chat messages, participant names, personal stories, or discussion details outside the meeting.

## **ACMCRN Special Events: Recording May Occur**

Some ACMCRN Special Events, such as educational presentations, webinars, panels, workshops, or guest speaker events, may be recorded for educational, outreach, or future viewing purposes.

When an event will be recorded, ACMCRN will make reasonable efforts to notify participants in advance through the event description, registration information, reminder email, verbal announcement, or on-screen notice at the beginning of the event.

By choosing to participate in a recorded Special Event, attendees understand that their name, image, voice, chat messages, or questions could be included in the recording if they choose to appear on camera, speak, submit a question, or participate in the chat.

Participants who do not wish to appear in a recording may choose to keep their camera and microphone off, avoid using identifying information in the chat, and submit questions only if they are comfortable doing so.

## **Medical and Health Information Disclaimer**

ACMCRN Peer Support Meetings and Special Events are intended for education, community connection, and peer-to-peer support. They are not a substitute for medical care, diagnosis, treatment, mental health services, legal advice, or professional medical guidance.

Information shared by participants, speakers, moderators, or guests reflects individual experiences and perspectives. It should not be understood as medical advice or a recommendation for any particular treatment, provider, medication, procedure, or care plan.

Always consult a qualified healthcare professional regarding questions about your health, symptoms, medications, treatment options, or medical emergencies.

If you believe you are experiencing a medical emergency, seek immediate help through your local emergency services or emergency department.

## **A Supportive Community**

ACMCRN recognizes that living with Arachnoiditis or Chronic Meningitis can be isolating, overwhelming, and deeply personal. Our goal is to create spaces where people feel heard, respected, and less alone.

Thank you for helping us maintain a safe, compassionate, and supportive ACMCRN community.

## **Medical Disclaimer**

ACMCRN Peer Support Meetings and Special Events are intended to provide education, connection, and peer-to-peer support. They are not medical appointments and do not provide medical diagnosis, treatment, counseling, crisis intervention, legal advice, or individualized medical recommendations.

ACMCRN moderators, hosts, guest speakers, volunteers, and participants may share personal experiences, general educational information, or resources. These comments reflect individual perspectives and should not be considered medical advice or a recommendation for any specific provider, medication, test, procedure, treatment, or care plan.

Please consult your qualified healthcare provider regarding your symptoms, medications, treatment options, medical decisions, or changes in your condition. Do not delay seeking professional medical care because of information shared during an ACMCRN meeting or event.

If you are experiencing a medical emergency, a mental health crisis, or feel unsafe, please contact local emergency services, go to the nearest emergency department, or seek immediate help from an appropriate qualified professional.

ACMCRN does not endorse or guarantee the accuracy, safety, effectiveness, or suitability of treatments, providers, products, services, or information discussed by participants or guest speakers.