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Building the next generation of PATIENT ADVOCATES

Instructor

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AGORA CONFERENCE 2026

More Than a Patient: Your Voice.
Your Life. Your RMD Journey.

WORKSHOP OBJECTIVES

1. Describe the **key skills and qualities** the next generation of patient advocates bring or need
2. Identify the main **barriers and enablers** to attracting and retaining younger advocates in patient associations
3. Leave with at least 1 **practical action** to support new advocate recruitment and retention

“Most of us joined because a diagnosis forced us to. The next generation is also finding us for different reasons, and if we don't understand those reasons, we'll lose them.”

EULAR Young PARE already connects rheumatology patient advocates aged 18–40 years across Europe… proof some of this generation is reachable now, not just hypothetical

WHO DO WE MEAN?



Millennials

1981 – 1996



Gen Z

1997 – 2012



Gen Alpha

2013 – 2025

WHAT DO THEY BRING?



Digital-native storytelling

Turning lived experience into short-form content and campaigns — often faster than legacy leadership.



More informed than ever

Arrive having already read the research and found the online communities — an asset to channel, not manage.



Not afraid to speak up

Expect to be heard quickly, not to earn a view over years.



Coalition-minded

Comfortable with cross-border, cross-condition solidarity rather than single-disease silos.



Low patience for hierarchy

Want to contribute meaningfully quickly, not “wait their turn.”

WHAT DO THEY NEED?



Structure without bureaucracy

A clear role and a clear ask — not a long constitution to read first.



Flexibility

Asynchronous, modular involvement matters more than committee attendance.



Two-way mentorship

Pairing, not just onboarding.



A gap worth filling

A genuine, meaningful gap their involvement would close — not a vague invitation to “get involved.”

WHAT ARE THE BARRIERS?

Rigid governance

Fixed board terms, in-person-only or daytime-only meetings, formal minutes.

“Prove yourself first” culture

Years of quiet contribution before a real voice.

Recognition gone stale

Certificates and titles matter less than visible impact and networked opportunity.

Founder / legacy-leader identity fusion

One person’s story can unintentionally crowd out new narratives.

Limited attention span

Long meetings and slow governance lose this generation fast — format matters as much as substance.

SPOTLIGHT

YOUNG ADVOCATES BRANDED “SICKFLUENCERS”



Recent, largely negative media coverage of young people turning chronic illness into a ‘lifestyle trend’ has sparked swift backlash across the online chronic illness community

Associations
may be slow to trust a highly online active younger advocate

Newer and younger advocates
may hold back from visible advocacy or getting involved in broader advocacy circles to avoid being ‘labelled’

WHAT ARE SOME KEY ENABLERS?

Short, visible, high-agency projects

A campaign or defined pilot as an entry point before board-level commitment.

Peer-to-peer buddy systems

Rather than top-down onboarding.

Explicit succession conversations

Naming that leadership will change hands, and when.

Public, immediate credit

Not saved for an annual dinner.

Make it exciting, not just worthy

Frame involvement as genuinely interesting or fun — not only a moral appeal.

GROUP ACTIVITY · 35 MINUTES

Over to you

I've done the talking — now it's your turn to do the real work.

35:00

STEP 1 · 10 MIN

Barriers

Every real barrier you've hit or seen around your topic. Be specific: not "lack of resources", but what actually happened.

STEP 2 · 10 MIN

Enablers

What has worked, in your association or one you've heard of, to get past each barrier?

STEP 3 · 15 MIN

MOST IMPORTANT

One action

Each person commits, out loud, to ONE concrete action they'll take back to their own association. Your action, not the table's. Write it next to your name on the flipchart.

1

TABLE 1 · FACILITATOR: SIMON

Finding & Onboarding

Attracting new and younger advocates, and their first 90 days in the association.

2

TABLE 2 · FACILITATOR: SOUZI

Retention & Leadership

Staying involved, growing into leadership, and avoiding the "prove yourself first" trap.

14:40 REPORT-BACK

2–3 min per table: the one barrier, enabler and action that most surprised or energised you.

Pick a spokesperson — not Simon or Souzi!

HEADLINE MESSAGES FOR PLENARY



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THANK YOU!

Contact me