



IgG4ward! EuroJAM Key Takeaways & Viewing Guide: Understanding Medications and Managing Side Effects in IgG4-Related Disease

Accompanying Dr. Maria Leandro and Comfort Dawodu's session

Importance of this talk

Medications play an important role in treating IgG4-related disease (IgG4-RD). They can help reduce inflammation, control disease activity, maintain remission, and protect organs and tissues from damage.

Understanding why these medicines are used, what side effects may occur, and when to speak with your healthcare team can help patients and caregivers feel more informed throughout treatment.

In this interactive breakout session, **Dr. Maria Leandro**, Consultant Rheumatologist at University College London Hospitals, and **Comfort Dawodu**, Advanced Clinical Practitioner at Oxford University Hospitals NHS Foundation Trust, discuss medications used to treat IgG4-RD.

The session focuses particularly on steroids. Steroids can work quickly to control inflammation, but they can also cause side effects, especially when used at higher doses or for longer periods of time.

Through expert discussion, audience questions, and shared experiences, the session explores infection risk, vaccinations, blood sugar and digestive changes, mood and sleep, swelling, appetite and weight changes, bone and muscle health, and the importance of ongoing treatment monitoring.

This guide highlights key themes from the presentation and provides a roadmap for viewers as they watch the session.

Key takeaways

- Medications can help control inflammation and protect against damage from IgG4-RD. Treatment may be used to reduce inflammation, control disease activity, maintain remission, and help protect affected organs and tissues.

- Steroids can work quickly to control inflammation, but they can also cause side effects. The session discusses possible short- and long-term effects and what patients can look out for while taking them.
- Steroids may affect different parts of the body. Possible effects discussed during the session include changes in blood sugar, indigestion, infection risk, mood and sleep changes, swelling and fluid retention, increased appetite and weight changes, bone thinning, skin changes, eye problems, and muscle weakness.
- People taking steroids or other medications that suppress the immune system may need to be more careful about infections. The speakers discuss handwashing, avoiding close contact with people who are clearly unwell, and seeking medical advice when symptoms of infection develop.
- Vaccinations are an important topic to discuss with your healthcare team. The session explains that some medications can affect the body's response to vaccines and that live vaccines may not be appropriate with certain treatments.
- Steroids can affect mood, energy, sleep, appetite, and physical appearance. Family members and friends may sometimes notice changes that the person taking the medication has not recognized. The speakers encourage patients to discuss changes that are affecting daily life or relationships.
- Steroid-related weight and body changes are not only about food. The session explains that steroids themselves can affect the body and how fat is distributed. Balanced meals and healthy choices may help with some effects, but they cannot prevent every steroid-related body change.
- Longer-term steroid use can affect bones and muscles. The speakers discuss bone thinning, bone-density scans, calcium and vitamin D when prescribed, movement, physiotherapy, and exercises that can be adapted to an individual's abilities.
- Movement matters, but so does pacing. Walking, swimming, chair-based activity, and gradually building strength are discussed as possible ways to stay active. Audience members also share the importance of balancing activity with rest.
- Steroids should not be stopped suddenly. The speakers emphasize that steroid treatment may need to be gradually reduced, or tapered, rather than stopped all at once.
- Monitoring is part of treatment. Regular blood tests can help the healthcare team understand how well the disease is controlled and whether treatment may be causing problems.

Watch for these moments in the session

As you watch Dr. Maria Leandro and Comfort Dawodu's discussion, pay particular attention to:

- What DMARDs, immunosuppressants, and immunomodulators mean
- Why medications are used to control IgG4-RD

- Why steroids can be useful for quickly reducing inflammation
 - Common short-term side effects of steroids
 - Infection risk and practical ways to help protect yourself
 - The audience discussion about vaccinations and immunosuppression
 - How steroids may affect mood, irritability, energy, and sleep
 - Swelling, increased appetite, weight changes, and other body changes
 - Longer-term effects on bones, skin, eyes, and muscles
 - The discussion about movement, exercise, physiotherapy, and pacing
 - Why steroids should not be stopped suddenly
 - Why blood tests and ongoing medication monitoring are important
 - The final audience discussion about healthy eating, supplements, and medications that suppress the immune system
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Why this matters

Living with IgG4-RD can involve both managing the disease and managing the effects of treatment.

Throughout the session, Dr. Maria Leandro and Comfort Dawodu encourage patients to understand what their medications are for, recognize changes in how they feel, and communicate concerns with their healthcare team.

The discussion also shows why the people around you can be important. Family members, friends, and caregivers may notice changes in mood, energy, or appearance and can help support conversations about side effects.

Most importantly, the speakers emphasize that patients should not feel they have to manage medication concerns alone. Asking questions, reporting new or changing symptoms, and completing recommended monitoring are all important parts of treatment.

Understanding both the benefits and possible side effects of medications can help patients and caregivers become more informed partners in their care.

Helpful terms:

DMARD (Disease-Modifying Antirheumatic Drug): A name used for medications that help modify the disease process. In the session, Dr. Leandro explains that these medicines are not painkillers. Instead, they affect the immune system over time to help suppress inflammation and reduce the risk of damage.

Immunomodulator: A medication that changes or modifies how the immune system works.

Immunosuppressant: A medication that suppresses, or reduces, activity in the immune system.

Opportunistic infection: An infection that may cause illness when the immune system has been weakened or suppressed, even though it might not normally cause problems in someone whose immune system is working normally.

Steroids: Medications that can quickly reduce inflammation and immune-system activity. The session describes steroids as an important treatment for bringing inflammation under control, while also explaining the side effects that can occur.

DEXA scan: A bone-density scan. The speakers discuss DEXA scans as one way clinicians can check for bone thinning in people who may be at higher risk.

Tapering: Gradually reducing the dose of a medication. The speakers emphasize that steroids should not be stopped suddenly and may need to be reduced gradually.

Medication monitoring: Regular checks, including blood tests, that help the healthcare team understand how well treatment is controlling the disease and whether the medication may be causing harm.

Continue Learning

Whether you are newly diagnosed, supporting a loved one, or seeking to deepen your understanding of IgG4-related disease, the **IgG4ward! Academy** offers educational resources developed specifically for patients, caregivers, and healthcare professionals.

Explore disease education modules, expert-led learning content, and updates on research and treatment developments.

Learn more at www.igg4ward.org

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