What does it feel like to be a patient?

Remember:
You add value & insight to healthcare & how it is provided
PAMs
PREMs
PROMs
Concept of Perspective

Just because you are right, does not mean, I am wrong.
Medicines used to treat Vasculitis
<table>
<thead>
<tr>
<th>Immune system modifying drugs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rituximab</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cyclophosphamide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Azathioprine</td>
<td>Imuran®</td>
<td></td>
</tr>
<tr>
<td>Methotrexate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mycophenolate</td>
<td>Cellcept®</td>
<td></td>
</tr>
<tr>
<td>Immunoglobulin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Steroids – Prednisolone</td>
<td>Deltacortril®</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supportive Medicines</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bone Protection</strong></td>
<td>Kalcipos®</td>
<td>Alendronate, Alendronic Acid</td>
</tr>
<tr>
<td>Calcium &amp; Vitamin D</td>
<td>Calcichew®</td>
<td>Fosamax®, Fosavance®</td>
</tr>
<tr>
<td></td>
<td>Desunin®</td>
<td></td>
</tr>
<tr>
<td><strong>Stomach Protection (PPIs)</strong></td>
<td>Esomeprazole, Omeprazole, Lansoprazole</td>
<td></td>
</tr>
<tr>
<td><strong>Blood Pressure Control</strong></td>
<td>Bisoprolol, Amlodipine, Irbesartan</td>
<td></td>
</tr>
<tr>
<td><strong>Infection prevention</strong></td>
<td>Septrin (Co-trimoxazole), Nystatin</td>
<td></td>
</tr>
<tr>
<td><strong>Other Medicines</strong></td>
<td>Apixaban, Paracetamol, Serc, Simvastatin, Dymista, Duloxetine</td>
<td></td>
</tr>
</tbody>
</table>
How do the medicines work?

Complex!
Immunosuppression – what do you need to think of?

Side-effects of individual medicines

Managing side-effects of medicines, e.g. bone protection if taking steroids

Infection risk & exposure to people with infections

Skin protection

Wound healing

Sick day rules for some drugs, e.g. steroids

Vaccines

Effects on fertility/pregnancy & breast-feeding issues
## They do what?

<table>
<thead>
<tr>
<th>Drug</th>
<th>How does it work?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclophosphamide</td>
<td>DNA of immune cells is affected (alkylating agent)</td>
</tr>
<tr>
<td>Rituximab</td>
<td>Monoclonal antibody – CD20 protein (“antigen”) on surface of B cells</td>
</tr>
<tr>
<td>Glucocorticoids</td>
<td>Effects T-cells and cell messenger systems</td>
</tr>
<tr>
<td>Tacrolimus</td>
<td>Calcineurin Inhibitor (T-cells)</td>
</tr>
<tr>
<td>Mycophenolate</td>
<td>IMPDH (enzyme) Inhibitor (T-cells &amp; B-cells)</td>
</tr>
<tr>
<td>Sirolimus</td>
<td>mTOR inhibitor (T-cells)</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>Antimetabolite immunosuppressant – effects an enzyme at cell level</td>
</tr>
<tr>
<td>Azathioprine</td>
<td>Antimetabolite immunosuppressant – effects an enzyme at cell level</td>
</tr>
<tr>
<td>Avacopan</td>
<td>Blocks complement (Ca5) receptor</td>
</tr>
</tbody>
</table>
Antibodies are part of our immune system, our body uses them to kill infecting organisms like bacteria and viruses.

Antibodies are made by special B-lymphocytes (B-cells).

We are born with millions of B-cells, each of which recognises a different antigen through its B-cell receptor.

An antigen could be a protein on a bacteria or virus.

When the B-cell recognises an antigen, it releases its B-cell receptor into the bloodstream, which is now called an antibody.

The antibody triggers an immune response against the antigen.
Cyclophosphamide

- Infection risk
- Effect on bladder and urinary tract – fluid intake
- Blood in the urine
- Nausea & vomiting
- Monitor blood count, kidneys, liver
- Monitor lungs and heart
- Contraception & fertility issues
- Hair loss (Alopecia)
- Effect on blood sugars
- Stomach upset

Rituximab

- Drug Reactions
- Effects on the heart
- Infection Risk
- PML
- Hepatitis B Infection screen
- Tuberculosis (TB) infection screen
- Monitor blood count
- Avoid in pregnancy & breast-feeding
- Stomach upset
- Rash
# Mycophenolate

<table>
<thead>
<tr>
<th>Monitor kidneys &amp; liver</th>
<th>Effect mood &amp; sleep</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection</td>
<td>Headaches, dizziness</td>
</tr>
<tr>
<td>Stomach upset – nausea, diarrhoea, ulcers</td>
<td>Gout</td>
</tr>
<tr>
<td>Drug Interactions</td>
<td>Joint/muscle pain</td>
</tr>
<tr>
<td>Contraception – avoid in pregnancy</td>
<td></td>
</tr>
</tbody>
</table>

- Monitor electrolytes
- Monitor blood sugars
- Monitor cholesterol/lipids
- Monitor blood pressure
<table>
<thead>
<tr>
<th>Methotrexate</th>
<th>Azathioprine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitor kidneys/liver/lungs</td>
<td>Interaction with medication used to treat Gout (Allopurinol &amp; Febuxostat)</td>
</tr>
<tr>
<td>Drug interactions</td>
<td></td>
</tr>
<tr>
<td>Monitor full blood count</td>
<td>Monitor full blood count – TPMT enzyme check</td>
</tr>
<tr>
<td>Infection risk</td>
<td>Infection risk</td>
</tr>
<tr>
<td>Monitor closely if retaining fluid</td>
<td>Monitor kidneys, lungs, &amp; liver</td>
</tr>
<tr>
<td>Mouth/stomach ulcers &amp; upset</td>
<td>Take one hour before or 2 hours after milk or dairy</td>
</tr>
<tr>
<td>Vaccines</td>
<td>Drug Interactions</td>
</tr>
<tr>
<td>Contraception/Pregnancy</td>
<td>Protect skin</td>
</tr>
<tr>
<td>Vitamin B12 &amp; folic acid</td>
<td></td>
</tr>
<tr>
<td>Protect from sunlight</td>
<td></td>
</tr>
</tbody>
</table>
Steroids

Increased appetite, leading to weight gain  Skin thinning
Mood changes – irritable/anxious  Cataracts/Glaucoma
Difficulty sleeping – “alerting”  High blood pressure
Indigestion/heartburn  Affect wound healing
Increased risk of infections – chickenpox, shingles
High blood sugars or diabetes
Weakening of the bones
Avacopan interferes with the inflammatory response by blocking the protein C5a.

C5a is a member of the complement system, a family of proteins that plays an important role in immune response.

Complement proteins help recruit white blood cells to areas of infection or injury, to defend the body and promote healing. But in autoimmune diseases, white blood cells are recruited to healthy tissue, where they build up and cause damage.

It blocks the effects of C5a by targeting its receptor, C5aR. Blocking C5aR interferes with messages to white blood cells, so fewer are attracted to inflammation sites.
Biosimilar Agents…what’s “similar” about them

**Biological medicine** – medicine derived from living cells or organisms, consisting of large highly complex molecular entities which may be difficult to characterise.

A **biosimilar medicine (or ‘biosimilar’)** is a biological medicine that is developed to be highly similar, but not identical, to the licensed originator biological medicine and shows no clinically meaningful difference in terms of quality, safety, & efficacy.

Biosimilars must demonstrate that there are **no clinically meaningful differences** compared to the originator biological medicine in order to be approved by the European Medicines Agency (EMA).

The evidence acquired over ten years of clinical experience with biosimilars demonstrates that they can be used as safely and effectively in all their approved therapeutic indications as their originator biological medicines (1st biosimilar 2006)

**Regulatory bodies**, including the EMA and the Health Products Regulatory Authority (HPRA), have published guidance and information for healthcare professionals and patients in relation to biosimilars.
Where can I look for more information?

www.hpra.ie

www.ema.europa.eu

Biological and biosimilar medicines: What patients should know

The questions and answers in this document have been edited and approved for NALA's Plain English Mark.

WHAT IS A BIOLOGICAL MEDICINE?

A biological medicine contains an active substance that is produced from a biological source such as living cells. The active substance in a biological medicine is what makes the medicine work. Biological medicines are also called biologics.

Here are some biological medicines that you may have heard of:
- The hormone insulin, which is used to treat diabetes;
- Vaccines;
- Monoclonal antibodies, which are a type of protein that can bind to substances in the body. They are used to treat a wide variety of conditions such as cancer or arthritis.

Biological medicines are different to chemical medicines such as paracetamol or aspirin.

Chemical medicines are smaller and less complex than biological medicines. When chemical medicines are made, the active substance is identical in every batch and every brand.
Informing Patients

Focus groups prior to adoption

One to one patient consultation by trained clinician, nurse or pharmacist in lead up to the adoption

The utilisation of a patient information leaflet with Q&A section and contact details of relevant HCP if patients wish to discuss further

Patient letter to be sent out to patients explaining:

1. The planned change
2. How the decision has been undertaken
3. That clinical efficacy and safety have not been affected
4. That significant financial benefits will be achieved for the NHS and/or the trust
Video: EMEA Biosimilar Medicines

https://www.youtube.com/watch?v=YPjvVf4xwFg&list=PL7K5dNgKnawb3Iqri7Ilr5wbawP71jQJ&index=1
“Drugs don’t work in patients who don’t take them”

C. Everett Koop, US Surgeon General

Could we all just go for coffee now, or, is there anything else to consider?
Step 1
Diagnosis
Medicines prescribed
Time of change

Step 2
Developing understanding of your condition
Learn what your medicines are for
Adapting – time of change
Questions
Emotions
? Concern
? Fear
? Anxiety

Step 3
Medications: Side-effects
Change of brands
Change of drugs
Dose changes
Interactions

Step 4
Follow up appointments
Blood Tests
Other tests

Step 5
The journey and commitment to your medication and managing your condition is ongoing.....
“The road is long”

We understand

The Medication Journey

The road is long
If it’s a journey..........................

Don’t be a passenger

Be the driver
My Medicines is a list of all the medicines and supplements you take and some of their details.

Please fill in the My Medicines information inside this leaflet.

This is your record of your medicines. Please keep this document safe and bring it with you when coming to Tallaght Hospital or attending any healthcare appointment. If you become ill, you or a family member can bring this record to hospital.

We also ask that you bring all of your medicines, in their original boxes and containers if you have them, with you when coming to the hospital.

Your medicines list will help hospital staff treat you safely.

IMPORTANT
To fill out My Medicines you need all your medicines in front of you including prescribed, non-prescribed and over the counter medicines. If you don’t know what medicines you take or you need help filling out My Medicines ask your pharmacist, doctor, friend or relative to help you.

www.tallaghthospital.ie

ZERO HARM
working together to improve safety

Information for patients and families
<table>
<thead>
<tr>
<th>Name:</th>
<th>My Family Doctor:</th>
<th>My Pharmacy:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>My Family Doctor Phone No.</td>
<td>My Pharmacy’s Phone No.</td>
</tr>
</tbody>
</table>

**The medicine I am allergic to:**

**Other Allergies:**

<table>
<thead>
<tr>
<th>Date I filled out this form:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of Medicine</th>
<th>The strength</th>
<th>How much medicine I take each time</th>
<th>I take it</th>
<th>I take it every day (Year/Day)</th>
<th>Why I take it</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC Tablets</td>
<td>25mg</td>
<td>3 tablets</td>
<td>Twice a day every morning &amp; evening</td>
<td>Yes</td>
<td>For my heart</td>
</tr>
</tbody>
</table>

Helps you to keep track of your medicines

More informed

Allows you to have more time with your consultant/doctor/nurse/pharmacist/dietician and focus on you
What do your medicines look like?
Thank you