

Navigating Vaccinations, Immunizations and FOP

Vaccinations can help individuals with FOP live healthier, more stable lives by reducing the risk of infections that could complicate or worsen existing issues related to FOP. However, because many immunizations are traditionally given intramuscularly, knowing the latest research and disease-specific recommendations is a critical part of the decision-making process as you navigate childhood immunizations and annual vaccines.

Working with Your Local Health Care Professional

While individuals with FOP and their families often end up as the experts in a hospital room, we encourage you to work with your primary care provider when making decisions about vaccine administration and which vaccines are most critical for your health. Sharing the following resources and support connections can help your provider be prepared and feel more confident helping you make these decisions.

- The International Clinical Council (ICC) on FOP is an autonomous, independent group of internationally recognized doctors who are clinical experts in FOP. The ICC shares best practices for clinical care and is available for consultation. You can find a list of FOP-trained doctors on pages 152-158 of the treatment guidelines at ifopa.org/treatment-guidelines
- The FOP Treatment Guidelines is a document written by members of the ICC to help guide local health providers. There is a section that specifically addresses vaccinations and immunizations on pages 70-82 of the treatment guidelines.

- Before approaching your doctor about vaccinations and FOP consider the following questions:
 - Does my doctor understand FOP?
 - Has my doctor seen the treatment guidelines?
 - Has my doctor connected with an FOP medical expert?
 - Does my doctor understand why I am being careful about vaccines?

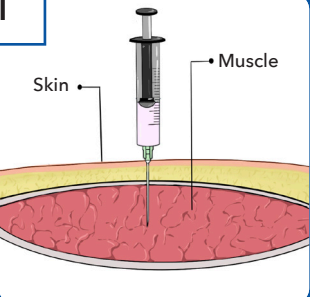
Understanding Vaccine Options and Processes

There are 4 main types of viruses used in vaccinations. Knowing which type of virus is used in the vaccine options you have is important.

1. Live Attenuated: Live virus which can't make you sick because it is inactivated (unless your immune system doesn't work well). These types of vaccines are contraindicated for people with FOP.
2. Inactivated whole virus: A dead virus that cannot replicate inside the body
3. Component of the virus/bacteria: A protein from a virus infection that will make your body recognize the real virus
4. mRNA: Gives a signal to your body as though a virus has been detected (but no virus is involved)

Viruses are administered in one of four common ways:

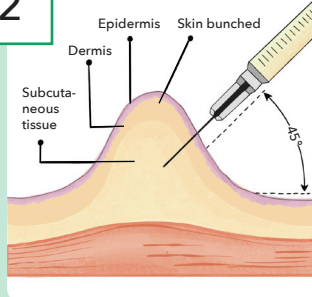
1



Intramuscular: administered in a muscle. (Injecting in the muscle is contraindicated for those living with FOP.)

The diagram shows a cross-section of skin and muscle. A syringe is shown injecting into the muscle layer. Labels include 'Skin' and 'Muscle'.


2



Subcutaneous: Administered just under the skin (before hitting the muscle)

The diagram shows a cross-section of skin layers: Epidermis, Dermis, and Subcutaneous tissue. A syringe is shown injecting into the subcutaneous tissue, with the skin bunched up. A 45-degree angle is indicated. Labels include 'Epidermis', 'Dermis', 'Subcutaneous tissue', and 'Skin bunched'.

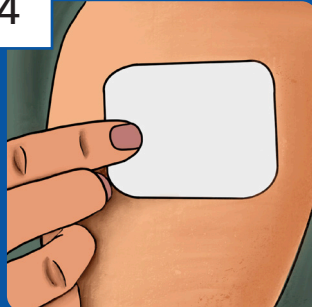
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Intranasal mist: administered inside the nose

The illustration shows a person's head in profile with a syringe being used to administer a mist into the nostril. A hand in a blue glove is holding the syringe.

4



Intradermal patch/transdermal patch: administered on top of the skin

The illustration shows a hand in a blue glove applying a white rectangular patch to the skin.

FOP-Specific Considerations for All Vaccination Situations

Important notes that apply to all immunization decisions:

- Those living with FOP should avoid ANY immunizations during an active flare-up
- Avoid immunizations within 2 weeks of a flare or flare-like symptoms.
- If possible, wait 6-8 weeks after a flare-up has ended because flare-ups can often occur around the same time.
- If you are going to inject intramuscularly, choose an injection site near a joint or muscle group already with HO, and where new bone won't cause a problem with mobility.
- For all patients, it is recommended to take a dose of acetaminophen or ibuprofen after receiving a vaccination
- If you are in a clinical trial, it is important to discuss any vaccines or therapies with your study doctors
- Vaccines are a Personal Choice!: Consider your personal health status/concerns and your environment when making a decision that is right for you.

Influenza (Offered Annually)

- If available a transdermal or intradermal vaccine is preferred
- Recommendation: receive the flu vaccine using a modified protocol where the regular flu vaccine is given subcutaneously.
- Live attenuated flu vaccines are NOT recommended
- **If you suspect you have an influenza infection (or have proof) consider antiviral treatment (i.e. oseltamivir, Tamiflu®).

COVID-19 (Offered Annually)

- The ICC does not provide recommendations on whether a person with FOP should or should not receive a COVID vaccine.
- The ICC continues to recommend that COVID-19 vaccines be administered the same route that they are approved (i.e. intramuscular).

Diphtheria-Pertussis-Tetanus (DPT) vaccines (Offered from Infancy through Adulthood)

- These vaccines are not recommended due to the profound immune response associated with causing flare-ups (even when given subcutaneously.)

Measles, Mumps, Rubella (Varicella) Vaccine (MMR or MMRV) (Offered from Infancy through Adolescence)

- Both vaccines are recommended to be given Subcutaneously and appear to be safe for FOP patients with causing flare-ups (even when given subcutaneously.)

Inactivated Polio Vaccine (IPV) (Offered from Infancy through Childhood)

- Recommended to be given subcutaneously and appears to be safe for people with FOP.

Pneumococcal 23-valent Polysaccharide Vaccine (PPSV23) (Offered from Infancy through Childhood)

- Recommended to be given subcutaneously and appears to be safe for people with FOP.

Hepatitis A (Offered from Infancy through Childhood)

- Recommended to be given subcutaneously and appears to be safe for people with FOP.

Hepatitis B (Offered during Infancy)

- Recommended to be given subcutaneously and appears to be safe for people with FOP.

Rotavirus (Offered during Infancy)

- Most people will have received this vaccine before they are diagnosed. There are no specific guidelines about how/whether to give this.

Meningococcal serogroup B Vaccine (MenB) (Offered during Adolescence and Adulthood)

- Recommended to be given intramuscularly but for people with FOP should be given subcutaneously and appears to be safe for people with FOP.

Human Papillomavirus Vaccine (HPV) (Offered during Adolescence and Adulthood)

- Recommended to be given intramuscularly but for people with FOP should be given subcutaneously and appears to be safe for people with FOP.

Shingles Vaccine (Zoster or Shingrix) (Offered during Adulthood)

- For individuals with FOP 50 years of age and older, these vaccines should be given SubQ.

Disclosure:

Contact your local health department for your local jurisdiction regarding immunizations and exemptions. Other Vaccines that may be required in other areas of world should be consulted via FOP treatment guidelines and directly with your local healthcare provider.

For additional information about educating your family and friends about FOP and vaccinations and to watch a recording of the Immunizations and FOP webinar presented by Dr. Chris Scott, Pediatric Rheumatologist Children's Hospital of Eastern Ontario and member of the International Clinical Council on FOP visit ifopa.org/immunizations.