

CLINIC VISIT

B. Initial Interaction with Family at Clinic Visit

When families come in for a clinic visit it is important to greet them as they arrive and get them settled into the waiting area.

The initial time spent with the family should include:

- Obtaining consent if family is new to the study,
- Reviewing study procedures
- Answering any questions that the family may have
- Applying EMLA cream as needed

The clinic visit can then proceed with:

- Completing needed interviews, questionnaires, and other paperwork
- Obtaining biologic samples

New families and families with a child who is antibody positive will have more questions and require more time on the part of the phlebotomist.

Greeting

Upon arrival of family, introduce yourself and get family settled in playroom. If another phlebotomist already has a family in the playroom, ask kids if they would like to get a toy out of the playroom. After they have selected a toy, get the family settled in the “San Luis Valley” room – the one with the recliners.

Obtain/review consent

If it is the 9 month visit or the first time a family is being seen by DAISY review the consent form with them and have them sign it if they haven’t already done so. Be sure to point out to the family that:

[This section needs to be greatly expanded – what are the major points that need to be included when obtaining/reviewing consent? Look through the consent form and make a list of the major points.]

Review study procedures

Even if the family has been in the DAISY clinic before and has signed the consent form, it is still important to review the study procedures with them. Let them know that the visit will include: Questionnaires, height, weight, urine sample (if applicable), saliva sample, throat swab, rectal swab and blood draw.

Review basic information about diabetes and celiac disease

The description of the study and information about diabetes, celiac disease, etc., depends a lot on the family and their knowledge of everything. If you are speaking to a SOC family you probably will not have to speak much about Diabetes 1. If it is a NEC family who hasn’t been exposed much to diabetes or medicine in general, there will probably have to be an in depth discussion of diabetes, celiac disease, antibodies, etc.,

Make sure the family knows the difference between diabetes 1 and diabetes 2. Talk about what an auto immune disease is, and, give them a couple other examples of an autoimmune disease- e.g. rheumatoid arthritis, lupus, celiac disease, etc., Tell them that we will also screen for the TG and EMA antibodies for celiac disease. Explain what celiac disease is and it might even be helpful to draw a comparison between how in diabetes 1 antibodies “attack” the islet cells or parts of the pancreas that produce insulin vs. how in celiac disease the antibodies small intestine when you have an intolerance to wheat, oats, barley, rye and the gluten in them. In diabetes 1 it causes the pancreas to not produce enough insulin(the chemical in the body that breaks down sugars for the body to use). In celiac disease it causes injury and inflammation to the small intestine which brings about possible symptoms that we list in the celiac symptom questionnaire, if not treated properly. Explain that celiac disease is more common in people that have diabetes 1 and their relatives.

Talk to the family about the three antibodies for diabetes 1 we look for in our blood testing. Explain what happens if they develop antibodies in their blood. Tell them how often we would like to see them if they develop antibodies(every three to six months), and how often we will be seeing them if they are negative(yearly).

Talk to the family about how every part of the study is extremely important. We need to look at environmental factors, lifestyle, vitamins, diet, viruses, genetics and all their roles in developing diabetes.

Answer any questions the family may have

Families with children who are antibody positive. When a family comes in the first time after they have been told their child has one or more positive antibodies there may be a lot of questions from the parents. Some parents may think it is now inevitable that their child will become diabetic. On the extreme other hand they may be in total denial about what is going on. Let parents know that we now would like to follow their child even closer that we have been doing. Tell them that we need them to be watching for symptoms of becoming diabetic- increased thirst, urinating more frequently, decreased energy, vomiting without diarrhea, etc., We really would like to see them more frequently- every three to six months rather than yearly. If the child has two or more antibodies we give the family a glucometer and ask them to check the child’s blood sugar at least weekly. We also would like them to test their urine for glucose and ketones once in a while. Explain that at the clinic visits we will also be checking a blood glucose, HgbA1c, and a urine glucose and ketone.

Apply EMLA cream (done by front desk staff at arrival). See below:

Talk to all members of family who are having their blood drawn about EMLA cream. If the child is too young to understand, discuss this with the parents (of course!). Tell them about how it is put on, and it’s skin-numbing properties. Offer the cream to adults in the group, as well as the children. However, warn the adults (especially the hairy-armed fathers) that pulling the sticker off of their arm may be more painful than the needle stick itself. Clean the antecubital region of the arm with an alcohol pad to make sure other soaps and lotions don’t negate the effects of the EMLA cream. Apply a few squirts of EMLA cream to the clean antecubital area of both arms. Place a tegaderm patch over the EMLA cream. Squish the cream around under the patch to cover “blood drawing” area of the arm. If the child has long sleeves, make sure you pull them down over the patch area (carefully). This aids in the child “forgetting” about what is on his/her arm, and not picking and playing with the tegaderm patch.

3/2018

EMLA will be applied by clinic staff only for subjects who request EMLA. Ethyl Chloride spray will be offered as well.

Ethyl Chloride Spray Instructions:

Indications: Ethyl Chloride is a vapocoolant (skin refrigerant) intended to topical application to control pain associated with injections and IV placement.

Contraindications: Ethyl Chloride is contraindicated in individuals with a history of hypersensitivity or previous allergic reaction.

Directions:

Explain process to subject or parent if subject is too young. Make sure to explain the sensation of the spray is very cold.

Assess the site for the optimal