Appendix F **RESEARCH PARTICIPATION CHECKLIST**
(FOR PARTICAPANTS RECIVING COLLECTION KIT TO THERE HOME).

1. After agreeing to participate in a research study that requires donation of surgical specimens obtained during a medically prescribed surgical procedure, you will receive a kit.

2. Upon receipt of the kit, please notify Sarah Ziegler by phone or email. If the box has not been received, that will give us enough time to resolve any problems.

3. Open the box and examine the contents.

4. Read all instructions.

5. Please read and sign consent forms where indicated.

6. Open the styrofoam container and remove the freezer pack, which should be refrozen.

7. Packets that hold the containers that will be used for collection of specimens are to be refrigerated.

8. Keep the paperwork, return the singed consent forms, pre- paid FedEx label and styrofoam container into the original box. It might be helpful to have a small roll of packing tape to reseal the box, if necessary, and to keep it with the kit.

9. Before leaving for the hospital, place freezer pack and refrigerated packets holding the containers and blood tubes into styrofoam cooler. Make sure you also put any applicable consent and instruction forms, the pre-paid Federal Express Label, and packing tape are in the box, as well! If you or your child are admitted to the hospital the day prior to surgery, have the hospital refrigerate (but not freeze!) the box. If the box containing the samples is returned to the laboratory without the consent forms it will be destroyed.

10. Some hospitals will take care of packing up the box and having it picked up by Federal Express. In some cases you may be given the packets following surgery (don't worry - the contents are not visible!) and put them into the styrofoam container, take the box to the shipping / mailing room located in the surgical facility.

Samples are taken from exostoses that are being removed for medical reasons, and blood is drawn during surgery. It is also important to remember that there is no cost to participating families or hospitals.

I understand that participation in any research study will not affect my immediate healthcare; that participation is entirely voluntary; and that non-participation will not influence my medical treatment.

I also understand that by registering with the National MHE Research Registry. I am not obligated to become a member of any organization or support group, to participate in any research that is being conducted.

If you have any questions at all regarding the nature of the research or about the role that participants play, please feel free to call or email me.

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NOTE: THE FACILITY WHERE THE SURGERY IS PERFORMED WILL STILL BE RESPONSIBLE FOR PERFORMING ITS OWN PATHOLOGIC EXAMINATION AND SHOULD BE CAREFUL TO KEEP WHATEVER PORTION OF THE SPECIMEN IS REQUIRED FOR THAT PURPOSE.