

Many of you know I am on the DART clinical trial where I receive a combination of immunosuppressive drugs. I was asked many questions at the conference about how to get into a trial, and considering all the programs now being offered or soon will be, I thought it may help to go over the expected process. First I would like to emphasize the importance of these trials: it is the only way for researchers to gather enough data about what works and what doesn't, and the more of us that get into a trial the better it is for all future chordoma warriors. If you have a recurrence or have a tumor that is unable to be effectively removed or treated:

- Download the list of [clinical trials](#) from the [Chordoma Foundation](#) website.
- Discuss the options offered in your area with your oncology team to find the best option for you.
- If you have not already gathered copies of all your chordoma related records, do so, including a genetic study of your tumor.
- Although it often does not show the right markers for chordoma, most of the trials still seem to require that paperwork. I have learned to scan everything, including MRIs and other scans into my computer and download them to a thumb drive. Wherever you decide to apply for the trial, they will want to see everything before accepting you, and if you have it readily available on a thumb drive it all goes a lot faster.
- Most trials will also want 3 slides of your tumor. These can be sent directly from the pathology department to the trial. Most hospitals keep tissue samples for up to 10 years. It took me 4 months to gather everything when I applied for my first trial, and I became extremely frustrated when the post office lost my very heavy package of documents and had to resend everything. By the time I applied to a third trial, I was accepted in less than 7 days because everything they needed was on the thumb drive except the tissue samples.

So gather your records, get the list from the [Chordoma Foundation](#) and speak with your medical team. A cure may be out there for you, but you have to make the effort to get into a trial yourself.

Another tip from a group member: if/as you request remote (without travel) consultations, write a brief synopsis of your overall health including chordoma treatments to date, and ideally include post-op MRI/CT imaging on CD with reports, including surgical notes and pathology reports from the Patient Records department at the center you were treated at. Make copies, send copies, not originals.

Good luck!

