

Dear all,

Please see the below monthly registry updates. If you have any questions or concerns please let me know. There are a total of approximately **4785** records in the registry between new enrollees and converted files.

To help with understanding the percentage of the registry that has been converted based on Dr. Brandom's number of 4853 legacy records, we are approximately **99% converted** (only about 191 records to go). However, I believe some of the numbers provided in the legacy registry may be slightly off. Below is a break down per report type as we convert:

	Charts converted	Pittsburgh Reported legacy #	% converted
AMRA	906	974	93
AKA	285	280	102
BX	2850	3547	80
RSR	66	57	116
MHN	14	11	127
MHS	6	50	12

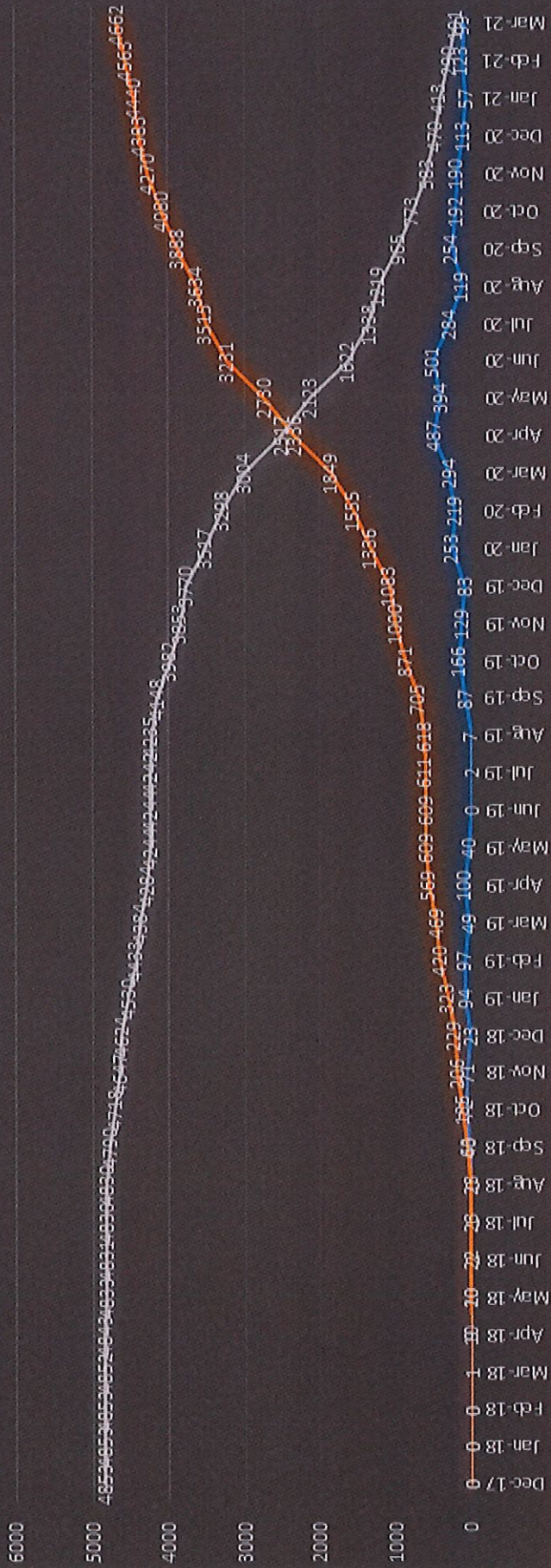
Below you can see how we now have more charts converted than not. A major accomplishment to date!

Legacy Chart Conversions

— Total legacy records to be converted

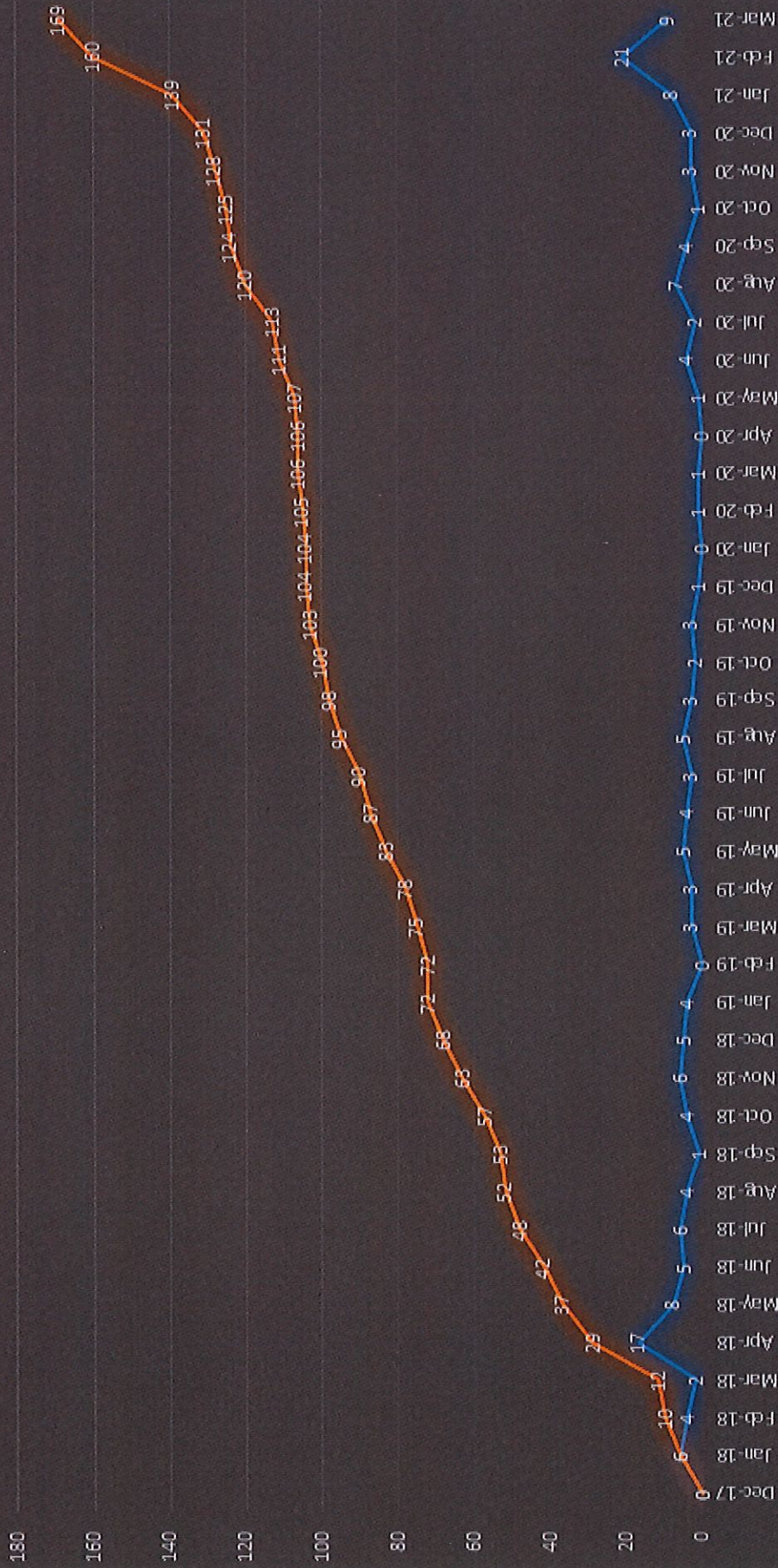
— actual number converted

— Number of legacy records converted



New NAMHR Enrollments

— New registry enrollees per month — Total new enrollees



Current Projects

- NAMHR updates
 - Working on adding Geisinger as a collaborating site so they can send patients and/or enter MH patients into the registry who RyR1 positive
 - 3/10/21 – working with them to answer IRB specific questions
 - Once all charts are converted will work on back log of biopsy reports that were sent to us by Dr. Rosenberg

- Wake Forest Biopsy reports
 - Marina from Wake Forest is starting to add biopsy reports to the registry online.
 - 3/29/21 – to date they have added 33 biopsies to the registry
- Minnesota
 - Talking to Cara Hinley (sp?) at Minnesota to get the biopsy from there entered into the registry
- Mayo
 - Reaching out to Mayo to see if they have any biopsies that need to be entered into the registry.
- Volunteers have been approved to return to campus and they are slowly being brought back to work on the registry.
- **Effectiveness of the Hotline getting events in to the Registry**
 - We are working to get MH Hotline calls into the registry
 - Kristy has identified 19 hotline calls between 8-24-20 and 2-16-21 that were thought to be MH.
 - We reached out to the callers to try and add work with them to add the cases to the registry.
 - 2/25 of the calls made it to the registry
 - 18/25 calls we have been unable to get in touch with the caller
 - 5/25 we have emails out to with no response yet
- **MH Hotline**
 - There has been a suggestion made to make a portal for real time entry into REDCap as sometimes by the time the calls are transcribed the notes are gone for the call (even a week later)
 - Will discuss with Teeda about potential for real time portal entry
 - Working on a few other edits that Teeda requested
 - Kristy is back to catching up the historical calls as well.
 - The last update on hotline surveys is as follows:
 - 269 consultant surveys sent, 102 answered
 - 269 caller surveys sent, 50 answered

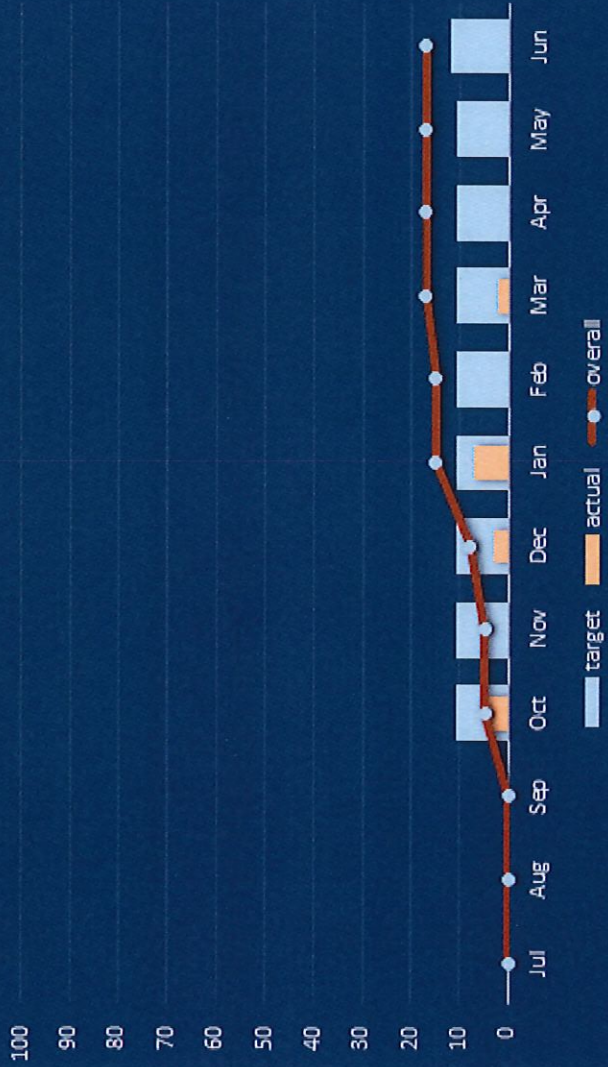
- Genetic project with Dr. Biescecker
 - Fifteen subjects enrolled to date
 - 10/17 have had their blood drawn and sent to NIH
 - 0/17 still need to sign the NIH ICF
 - 7/17 just sent kit to have sample drawn
 - 17 additional subjects to be contacted from our waiting list and first Registry search
 - Several subjects were excluded due to inability to contact them.

○ The below graph shows our enrollment goal of 11 per month in light blue, the actual number enrolled is over laid in orange so you can see if we are over or under our target for the month. The line is the overall enrollment trying to get to 100 subject.

Enrollment		
	target	actual
Jul	0	0
Aug	0	0
Sep	0	0
Oct	11	5
Nov	11	0
Dec	11	3
Jan	11	7
Feb	11	0
Mar	11	2
Apr	11	
May	11	
Jun	12	

100 17

MH Genetic Characteristic Enrollment



Amy M. Gunnett, RN, CCRC
Manager, Clinical Research
Malignant Hyperthermia Registry Manager (NAMHR)
 University of Florida, Department of Anesthesiology
 UF College of Medicine
 1600 SW Archer Road, PO Box 100254
 Gainesville, FL 32610
 Office Phone: (352) 273-8911 | Cell Phone: (352) 514-0489 |
 Research Fax: 352-273-5612 | Dept. Fax: 352-392-7029 |
 Email: agunnett@anest.ufl.edu
 Website: <https://anest.ufl.edu/research/>
 NAMHR Phone #: 1-888-274-7899
 Website: <https://anest.ufl.edu/namhr/>

