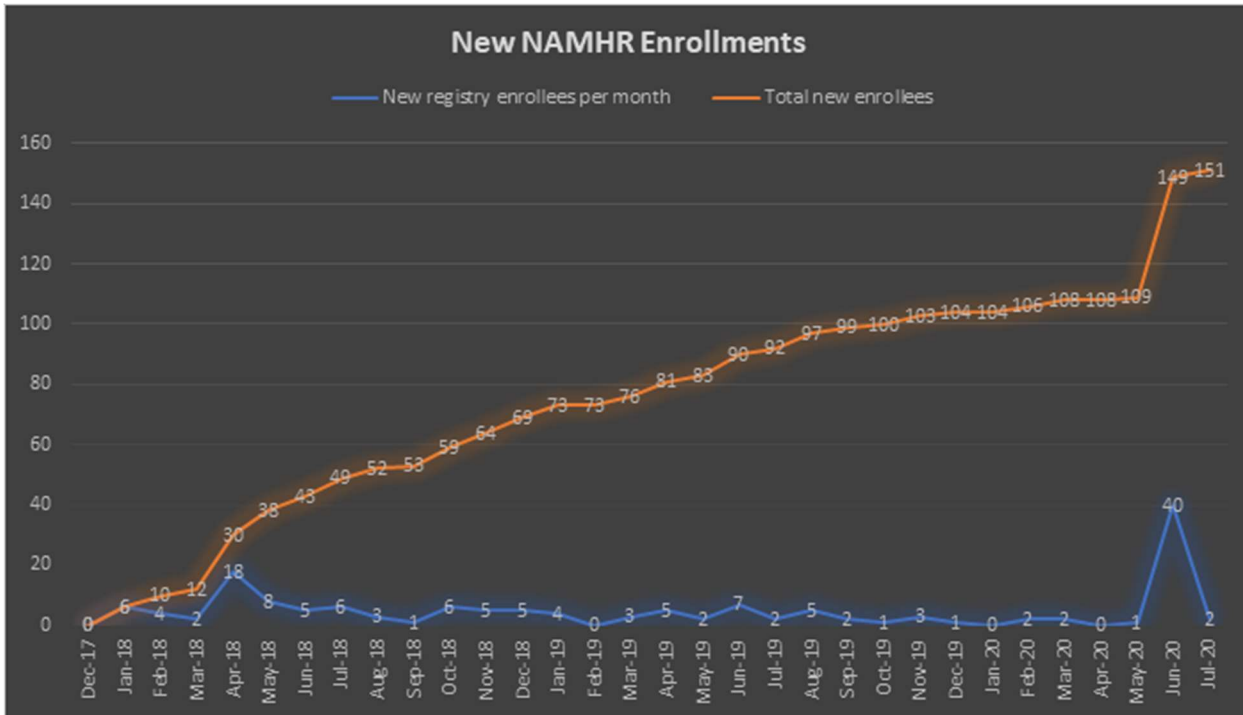


North American MH Registry of MHAUS Report

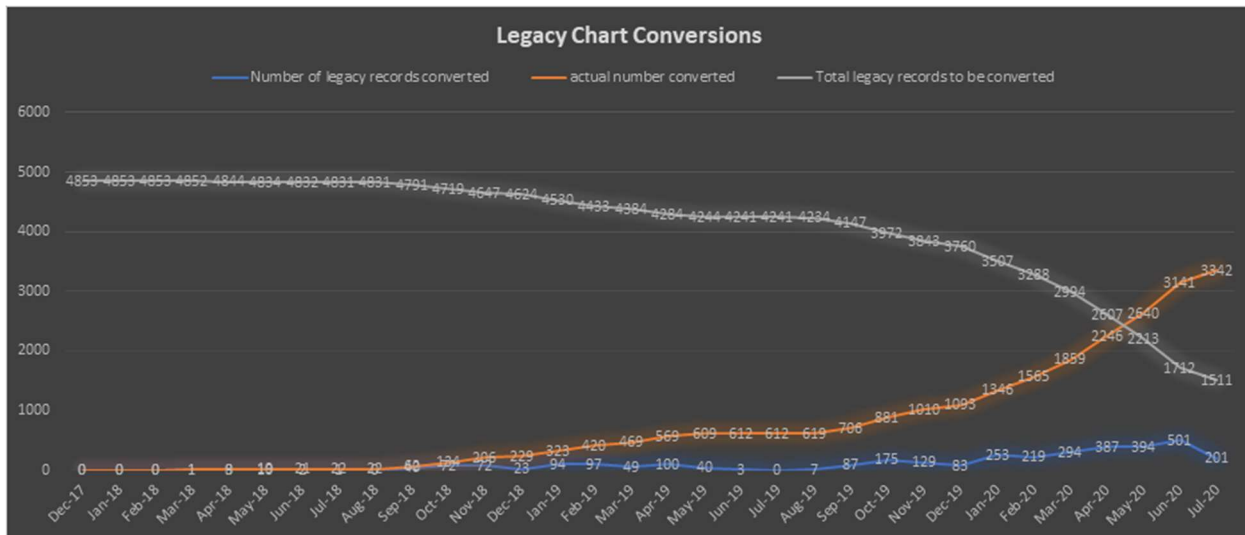
There are a total of approximately **3493** records in the registry between new enrollees (151) and converted files (3342). This is the most up to date information as of July 24, 2020 at 1530. Just a small explanation about the dramatic increase in newly enrolled. We've created new records for several family members (approx. 36) that had consents and/or reports but were filed with a different family member with no file of their own and account for the sharp incline between May and June.



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 **72% converted** (only about 1511 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	905	974	93
AKA	285	280	102
BX	1868	3547	53
RSR	67	57	118
MHN	15	11	136
MHS	7	50	14

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



Future Projects

- **Effectiveness of the Hotline getting events in to the Registry**
 - We are planning on doing a retrospective review of the hotline cases that were thought to be MH and comparing to see how many of those actually were registered in the registry in the last year.
- **MH Hotline**
 - MHAUS has asked us to take over the housing of the MH Hotline REDCap database
 - Gloria and Kristee have access to the UF REDCap for the Hotline now.
 - Working on getting Teeda access as well.
 - Working on finalizing some of the errors that occurred during the transfer
 - Working on updating the surveys to make them more usable for follow-ups.
- **Potential biopsy/genetic project**
 - PO has been set up with Dr. Biesecker’s lab
 - Started work on IRB, working on writing the protocol and consent form
 - Reached out to Quest about finalizing account set up, as of 7/24/20 this is still pending

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