

MHAUS/NAMHR updates:

Please see the below monthly registry updates. If you have any questions or concerns, please let me know. There are approximately **2100** records in the registry between new enrollees and converted files. This is the most up-to-date information as of April 16, 2020 at 1500.

Below are a couple of visuals showing the conversions and new enrollees:

Figure 1: A breakdown per month for the last 10 months

| | Jul-19 | Aug-19 | Sep-19 | Oct-19 | Nov-19 | Dec-19 | Jan-20 | Feb-20 | Mar-20 | Apr-20 | YTD Over the life of the registry at UF |
|------------------------------------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--|
| New registry enrollees per month | 2 | 5 | 2 | 1 | 3 | 1 | 0 | 2 | 2 | 0 | 108 |
| Data requests per month | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 11 |
| Number of legacy records converted | 0 | 7 | 87 | 175 | 129 | 83 | 253 | 219 | 294 | 197 | 2056 |
| New visits to Registry page | 12 | 9 | 26 | 8 | 16 | 11 | 3 | 9 | 5 | 0 | 483 |

Figure 2: New NAMHR Enrolments

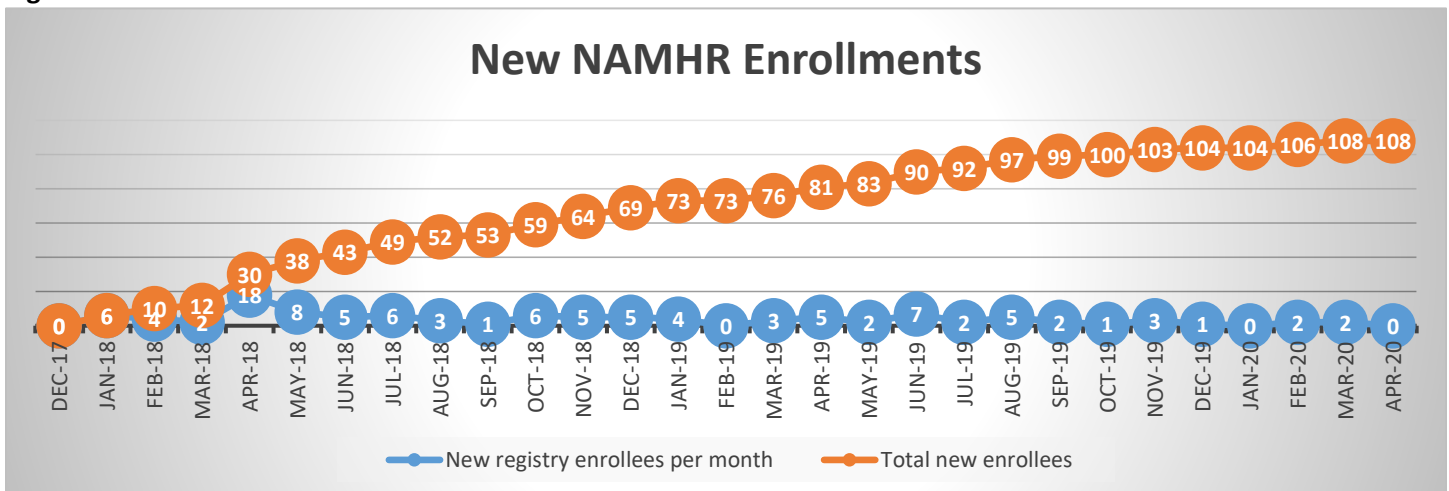
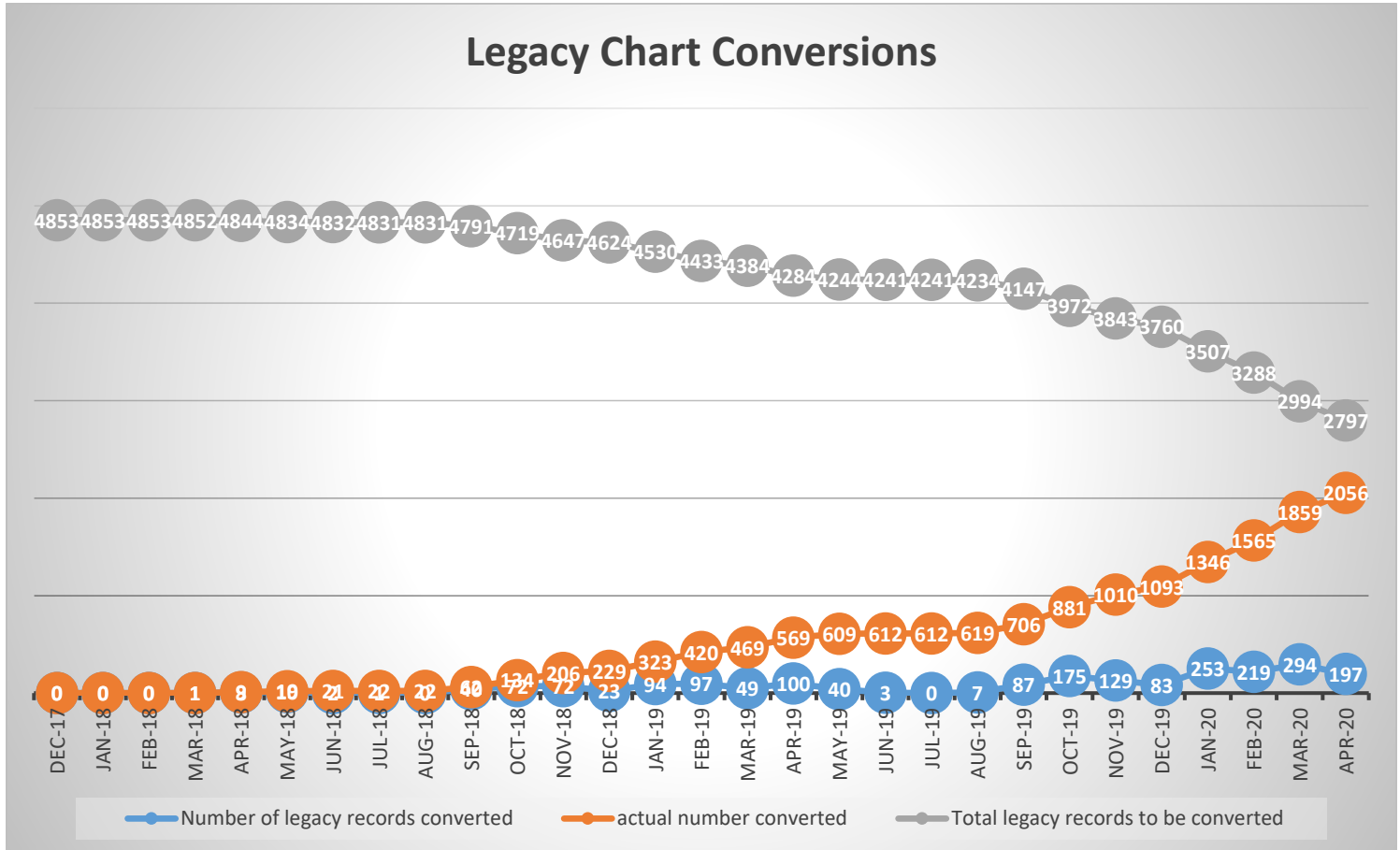
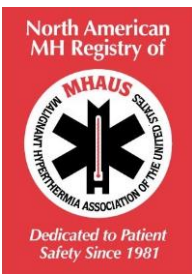


Figure 3: Legacy conversions



Current Projects

- **Evolving use of Dantrolene**
 - With the help our student volunteers, we are looking retrospectively at the evolving use of the Dantrolene brands since the release of Ryanodex.
 - Hope to have some abstract/publication by the end of summer or fall.
 - Approved by the IRB on 7-2-19.
 - Data pull done, analysis underway
 - Working on second data pull
 - Abstract finalized, submitted, and **accepted** to IARS
- **MH Hotline**
 - MHAUS has asked us to take over the housing of the MH Hotline REDCap database
 - IRB is approved the move of the Hotline database
 - Contract/Data Use agreement has been finalized
 - Data has been transferred from CHOP to UF
 - Working through a few issues with the data transfer
 - Will be reaching out to Teeda soon to see if there are any revision that are wanted to REDCap



- **COVID-19**

- COVID-19 calls coming into the Hotline
- Dr. Rosenberg and others created a specific COVID-19 and dantrolene use questionnaire for these calls
- MH Hotline IRB revised to include COVID-19 questionnaire
- The IRB has approved this addition
- REDCap will be revised to include this new questionnaire

Future Projects

- **Genetic project with Dr. Biesecker**

- The study will draw blood samples from MH patients and their family member and some exertional heat illness patients for full exome analysis by Dr. Biesecker at the NIH.
- Rough draft of proposal with UF Statistician
- Working with Quest on a contracting so patients can go into get their blood drawn and not worry about cost or shipping
- Working with Dr. Biesecker on funding.

- **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.

- **Potential Biopsy project**

- Working on a potential new biopsy test