

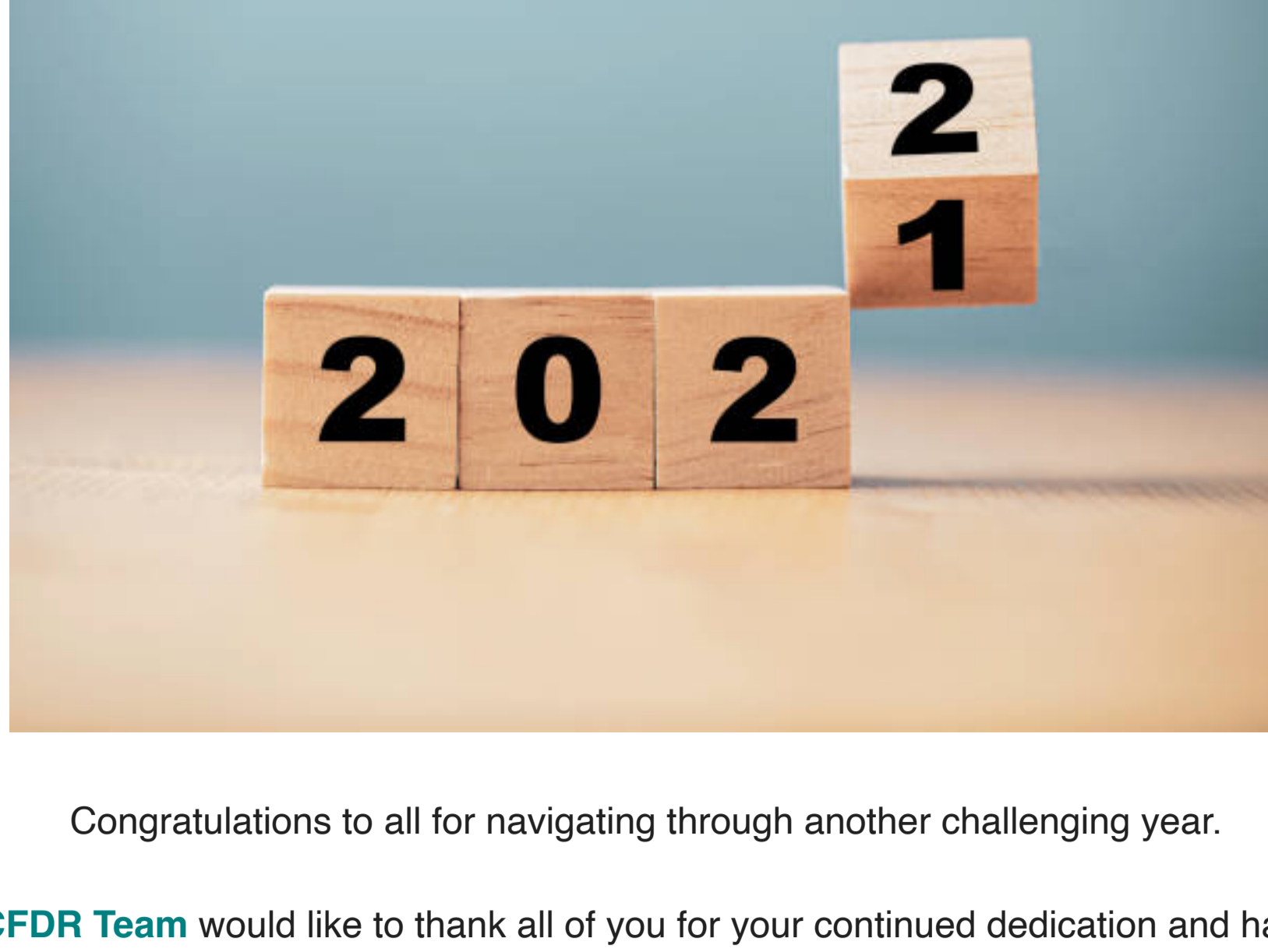
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Welcome to the ACFDR Newsletter

Issue #14

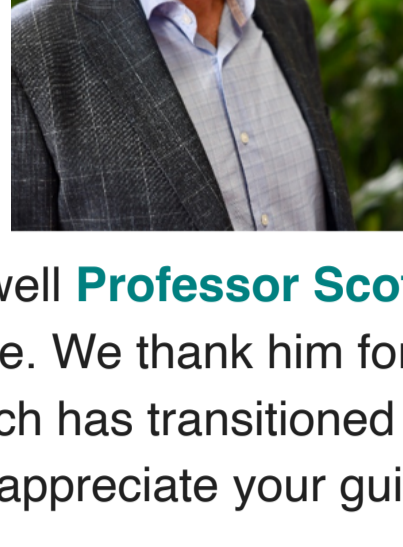
December 2021



Congratulations to all for navigating through another challenging year.

The ACFDR Team would like to thank all of you for your continued dedication and hard work. The ACFDR would not be where it is today without your contributions.

Steering Committee Updates



At the end of 2021 we farewell Professor Scott Bell as Lead Chair of the ACFDR Steering Committee. We thank him for his support of the ACFDR over the last 5 years, which has transitioned to a modern registry with excellent outputs, we appreciate your guidance and leadership

We also would like to acknowledge retiring SC members, Nettie Burke, Professor Claire Wainwright, Professor Peter Middleton, Susannah King and Lucy Keatley for their contributions and dedication to continually improving the registry.

Conjoint Professor Peter Wark will move into the position of Lead Chair, commencing 2022.



Andre Schultz will be taking the position of Deputy Chair



We look forward to an exciting 2022 for the ACFDR



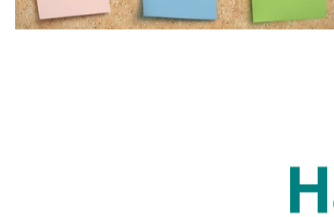
2021 Data Entry Deadlines

Table with 2 columns: 2021 Data Entry Required, Deadline for payment. Rows include Q1 2021 (31st May 2021), Q2 2021 (31st August 2021), Q3 2021 (30th November 2021), and 1. Q4 2021, 2. 2021 Annual Data, Complications and treatment. (28th February 2022)

Quarter 4 & the Annual Forms for 2021 will be due 28th February 2022.

This includes all clinical measures, hospital/clinic visits/ microbiology and completion, the quarterly sign off form, complications and treatment forms and the Annual sign off form.

Those sites who will send through their data via templates for upload, we would appreciate this 1 week prior to the deadline date.



REMINDERS

Have you updated the CFTR Modulator data for 2021

Each year in the Annual General Update form, you are asked if the participant has undergone treatment with CFTR modulators.

This serves as a reminder to update the ongoing status in the CFTR modulator form, to ensure the record has the most up to date information for the 2021 survey year.

Do your records have the most updated transplant data recorded?

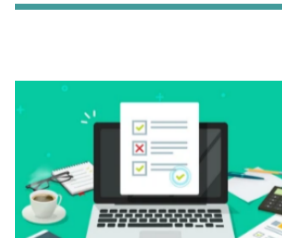
The Annual General Update is a great reminder to update your participant status on the transplant form, this also can always be entered retrospectively if data has been missed for previous years

Variants updated

We have significantly updated the variant list in accordance with the latest information received from John Hopkins University, and the ACFDR now holds the most up to date information



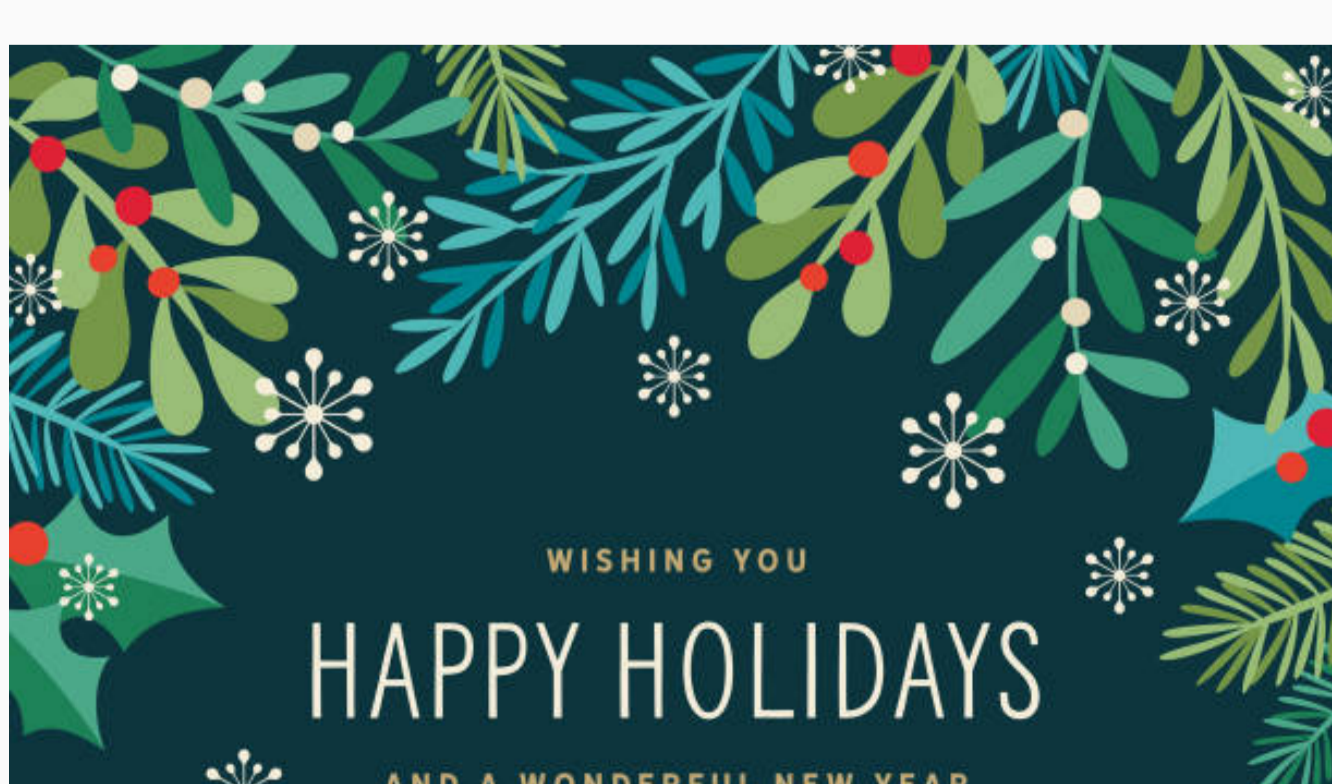
Did you know you can type part of the variant directly into the data field and all matching variants will pop up, instead of scrolling through the list? This will minimise the use of the "other" field.



Transfer/Shared Records

Shared/transfer records – To limit any duplicate entries in the registry please feel free to contact the ACFDR Help desk on med-acfdr@monash.edu to clarify if a person is already in the registry or to receive any guidance.

Notice any Mismatches? Get in contact with us if you notice any errors, we're here to help keep the data clean and up to date.



The ACFDR team will be taking a break over the festive season. Our office will be closed

Thursday 23rd December 2021 through to Monday 3rd January 2022.

We wish you all a happy and safe holiday season and are looking forward to an exciting new year.

Project Details

Project Leads

Academic Lead: Prof Susannah Ahern; Clinical Lead: Prof Scott Bell

Project Contacts

Marisa Caruso - Registry Coordinator; Dr. Rasa Ruseckaitė - Data Manager & Senior Research Fellow

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