

# CF CARE & COVID-19

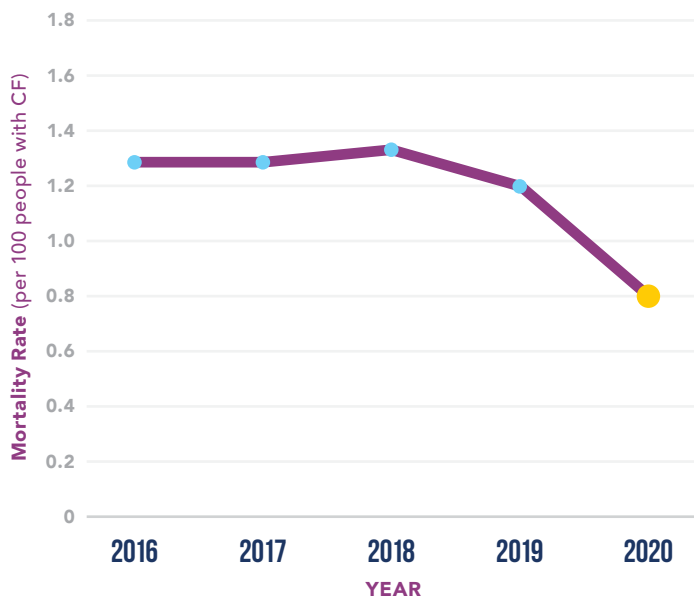
## 2020 PATIENT REGISTRY DATA



Throughout 2020, people with CF managed their health amid disruptions to daily life by the COVID-19 pandemic. Data captured in the CF Foundation's Patient Registry show remarkable trends in the health of people with CF and the care they received in partnership with their CF care teams – a testament to the strength and resilience of the CF community.

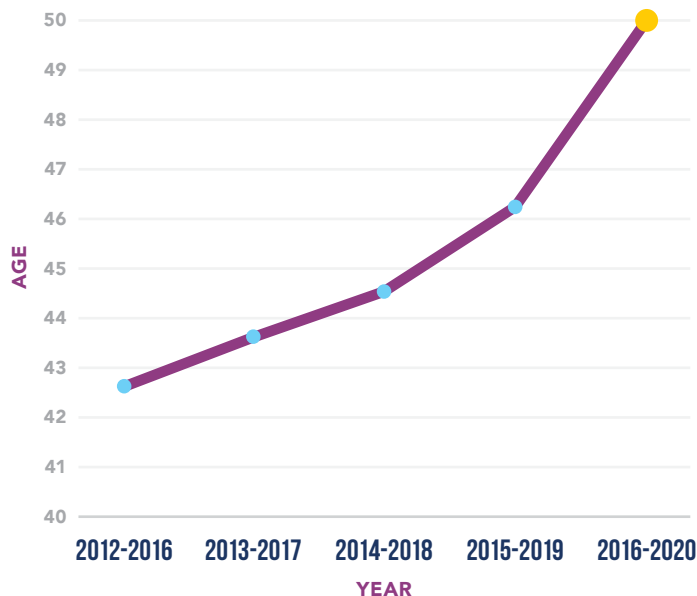
### REMARKABLE TRENDS

#### MORTALITY RATE



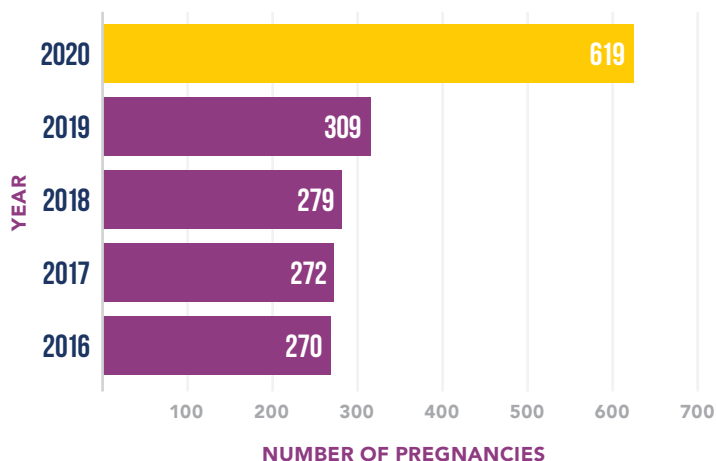
The mortality rate in 2020 was 0.8 deaths per 100 individuals with CF in the Registry. This is down from 1.2 deaths per 100 as reported in 2019 – and is part of a steady decrease in the mortality rate over the last 30 years.

#### SURVIVAL RATE



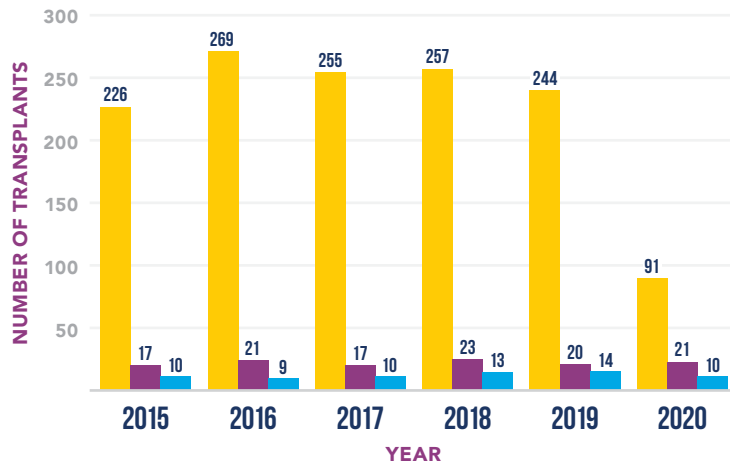
Between 2016 and 2020, the median predicted survival age was 50 years, up from 2015 and 2019, which was 46.2 years. This means that half of individuals born in the years from 2016 to 2020 are predicted to live beyond 50 years of age assuming present trends continue.

#### PREGNANCIES



Of the pregnancies reported in 2020, there was a sharp increase from what was a steady trend in the previous 20 years. Research is underway to understand why there was this increase and potential implications.

#### TRANSPLANTS BY TYPE



Among people with CF, the marked decrease in reported lung transplants is particularly notable when compared to liver and kidney transplants, which remained fairly constant from previous years.



# IMPACT OF THE PANDEMIC IN 2020

Registry data show how the pandemic affected the way people with CF experienced care in 2020. As more people with CF are living longer, research is being conducted to understand the impact of the pandemic and treatments like modulators, to improve how CF is treated now and well into the future.

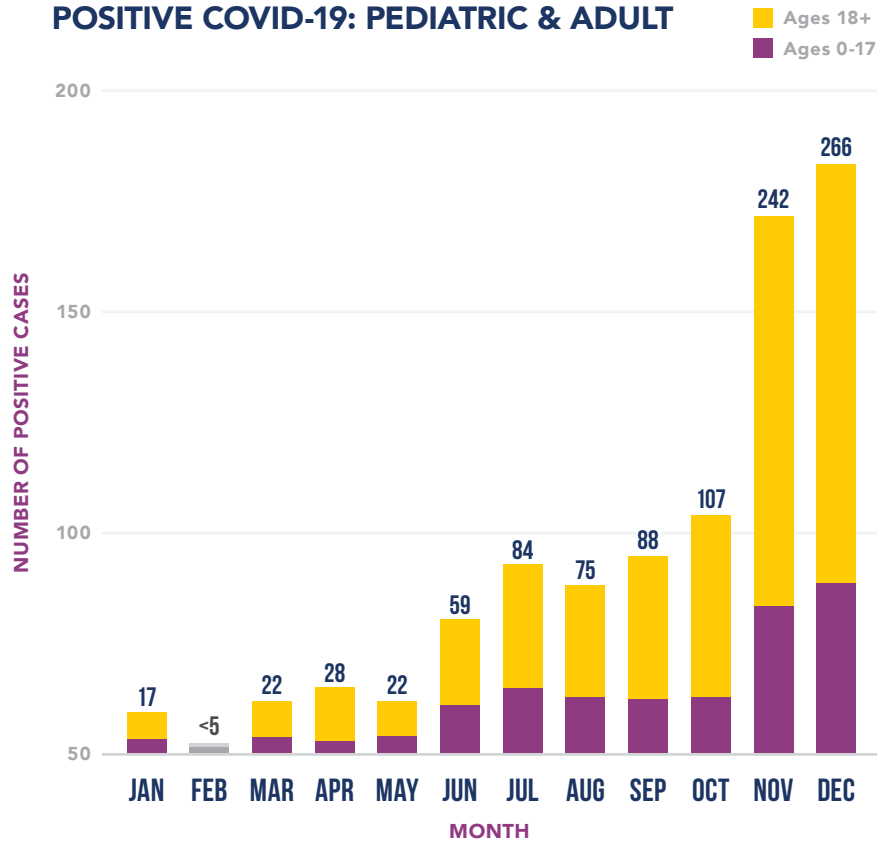
## POSITIVE COVID-19: RACE & ETHNICITY\*

	993 REPORTED COVID CASES	ALL PEOPLE WITH CF IN REGISTRY
% WHITE	92.2%	93.4%
% BLACK	4%	4.7%
% HISPANIC (ANY RACE)	13.3%	9.6%

\*Race not mutually exclusive

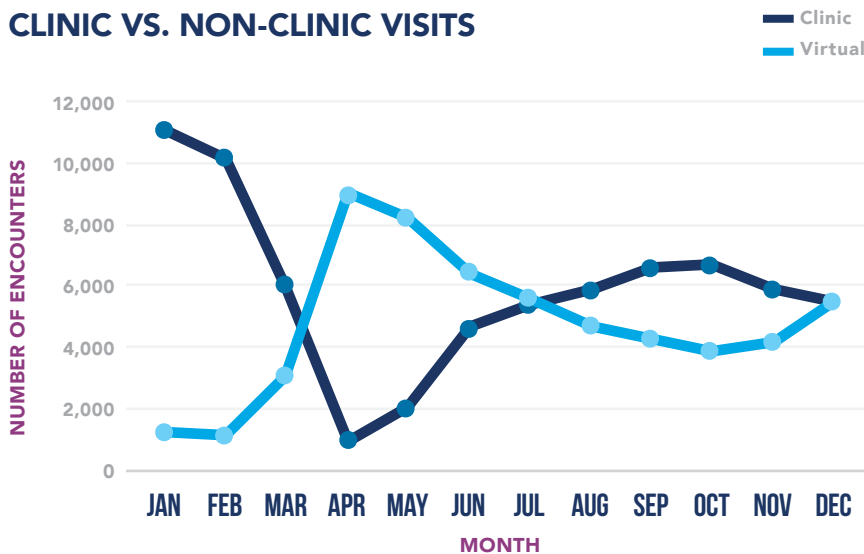
Of all reported to have tested positive for COVID-19 in 2020, those of Hispanic ethnicity were slightly over represented. These reports will be closely monitored to detect if this trend continues in 2021.

## POSITIVE COVID-19: PEDIATRIC & ADULT



Of those who tested positive for, or were otherwise diagnosed with, COVID-19 in 2020, there has been a steady increase in pediatric cases - as is the case with the general U.S. population.

## CLINIC VS. NON-CLINIC VISITS



The pandemic changed how people with CF experienced care. Notably, it accelerated the shift toward virtual visits via video or phone as infection prevention and control measures broadened so that the entire healthcare facility was better prepared to keep patients safer from COVID-19.

**i** The Patient Registry not only informed our understanding of how people with CF were affected by COVID-19 in the U.S., but was also part of a global effort to monitor outcomes of adults and children infected with the virus. Learn more about the published findings from the [Cystic Fibrosis Registry Harmonization Group](https://www.cff.org/PatientRegistry)

For more on the CF Foundation's Patient Registry, including the 2020 Patient Registry Annual Data Report, visit [cff.org/PatientRegistry](https://www.cff.org/PatientRegistry)

For your personal data in the Registry, ask your care team for your **Patient Summary Report**, accessed via CFSmartReports.

For CF-specific COVID-19 related questions and answers, visit [cff.org/COVID-19](https://www.cff.org/COVID-19)