

# WHAT IS A RARE CANCER?

Rare cancers are types of cancers that affect
<20,000
people per year<sup>1</sup>

1 in 4 cancers is considered rare<sup>2</sup> There are
200+
types of
rare cancer¹

# But numbers don't tell the whole story.

Rare cancers can also be defined by the challenges that are consistent among them.



#### Diagnosis can take a long time

- Rare cancers can be misdiagnosed or mistaken for other cancers.
- Symptoms may be unfamiliar or unusual.
- Doctors may not have experience with your particular tumor type.
- Extensive testing may be needed.



# Treatment options are limited, with more effective therapies urgently needed

- Lack of research data, financial viability, and small patient populations make developing treatments for rare cancers challenging.
- As a result, many people with rare cancers are treated with therapies or interventions intended for other cancers.
- Clinical trials can often offer the most effective treatment options, but are often lacking in rare cancers.



### Lack of research tools slows progress

- Lack of funding hinders researchers' ability to create dedicated research
  programs and develop the basic tools and data needed to make progress.
- As a result of smaller patient populations, there is less data to be studied.

<sup>&</sup>lt;sup>1</sup> National Cancer Institute. Surveillance, Epidemiology, and End Results Program. November 2020.

<sup>&</sup>lt;sup>2</sup> About Rare Cancers. National Cancer Institute. February 2019.

## Rare cancer patients and researchers need our help

Though tumor location, progression, and symptoms vary widely, there are many common challenges shared across the rare cancer community.



#### **Researcher Challenges**

- Bleak research funding landscape and lack of attention from major funding sources
- Challenge in recruiting young investigators
- Lack of publicly available research models, such as cell lines and mouse models
- Small and disconnected tissue sample repositories
- Difficulty in clinical trial recruitment due to small patient populations



#### **Patient Challenges**

- Delayed and/or incorrect diagnosis
- Often no established standard of care leading to treatments adapted from other cancers
- Lack of specific expertise by physicians
- Limited clinical trial options
- Inconsistent awareness of, and access to, biomarker testing
- Feeling of isolation and lack of community

Since 2009, TargetCancer Foundation has been systematically working with partners across the rare cancer community to address these challenges.



