

“My TriFIT Journey”: A study summary report for child and adolescent participants

Sarah da Silva

McMaster University

ABSTRACT

This report card was developed as part of the TriFIT study, which examines the effects of TRIKAFTA on health and well-being in children and adolescents with cystic fibrosis. It provides each participant with a personalized summary of measured outcomes, including body composition (muscle, bone, and fat), aerobic fitness, physical activity, and quality of life. The results are presented in a clear and accessible format for participants and their families, without comparison to other participants. The purpose is to support understanding of individual progress and highlight each participants contribution to the TriFIT study. Sharing results in this way helps make research findings meaningful to participants, turning study measurements into practical, easy-to-understand information about how they changed over a year.

KEYWORDS: cystic fibrosis, TRIKAFTA, pediatrics, personalized results, science communication

For correspondence:
dasils15@mcmaster.ca

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About the TriFIT Study

The TriFIT Study is a research project designed to better understand how children and adolescents with cystic fibrosis (CF) grow, move, and feel now that they are taking a new CF treatment, TRIKAFTA®.

Understanding Cystic Fibrosis

Cystic fibrosis (CF) is a genetic disease that affects the lungs and digestive system. This causes thick mucus buildup, leading to difficulties with breathing and digestion. Daily treatments are required to help manage the disease.

In recent years, new medications known as highly effective modulators (like TRIKAFTA®) have revolutionized care. With TRIKAFTA®, many people with CF are living healthier lives. However, it is important to understand how these improvements affect other aspects of patients health and wellbeing.

Purpose of “My TriFIT Journey”

“My TriFIT Journey” was created as a personalized report card to share each TriFIT participant’s study results in an accessible and engaging way. Rather than only focusing on numbers, this report card helps children, teens, and families see what their results mean. Highlighting both the participant’s contribution to the larger study and their individual progress, makes findings meaningful to participants and allows them to see their impact.

While “My TriFIT Journey” was originally designed for study participants, it also offers a model for how research findings can be meaningfully communicated back to children and families. By combining scientific accuracy with visual storytelling and simple language, this approach demonstrates how participant-facing science communication can foster understanding, engagement, and trust in research.

Dear [name],

Thank you for helping me with the TriFIT study!

Because you took part in this study, me, other scientists, and doctors know more about how to care for kids and teens who have cystic fibrosis, like you!

Please enjoy this roadmap of your TriFIT journey. We hope you learned lots of exciting things along the way!

Best wishes,
Sarah



My TriFIT Journey

Study ID: TF-M/F#

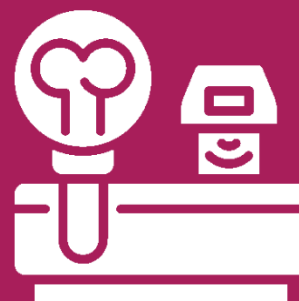
Age: # years old



I helped scientists learn what life is like for kids and teens with cystic fibrosis while they take TRIKAFTA. How? Let's see! →

BODY COMPOSITION

I did a full body scan on a dual x-ray absorptiometry machine (some people call it DXA) to look at how much bone, muscle, and fat I have.



FITNESS & FUEL

I did exercise tests on a treadmill to test my heart, lung, & muscle fitness and see how I use food as fuel during exercise.

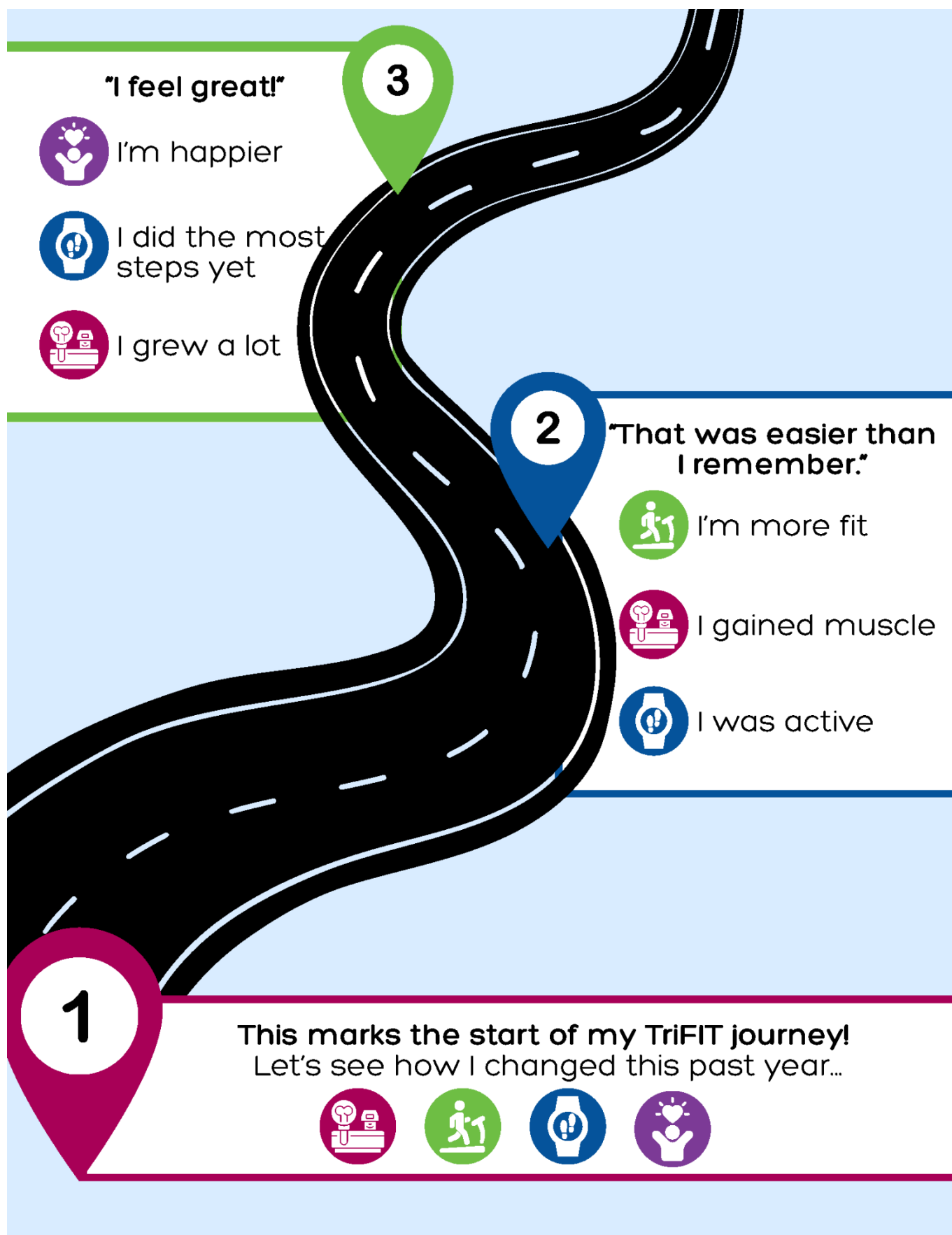
PHYSICAL ACTIVITY

I wore a GARMIN watch every day for one year to monitor my physical activity.



QUALITY OF LIFE

My parents and I completed surveys asking about my quality of life and well-being.



XX other children with cystic fibrosis participated in this study with me! With everyone's help, the scientists learned that...

The longer kids took TRIKAFTA, the stronger their bones and muscles were.



TRIKAFTA helps the lungs, heart, and muscles use fuel better, helping kids exercise longer!



Everyone was active! Most participants met the recommended activity guidelines.



All participants' quality of life continues to improve with TRIKAFTA.



This means that TRIKAFTA may be helping kids and teens with cystic fibrosis live healthy, active lives!