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Welcome to the February 2024 issue of the STXBP1 Foundation Newsletter

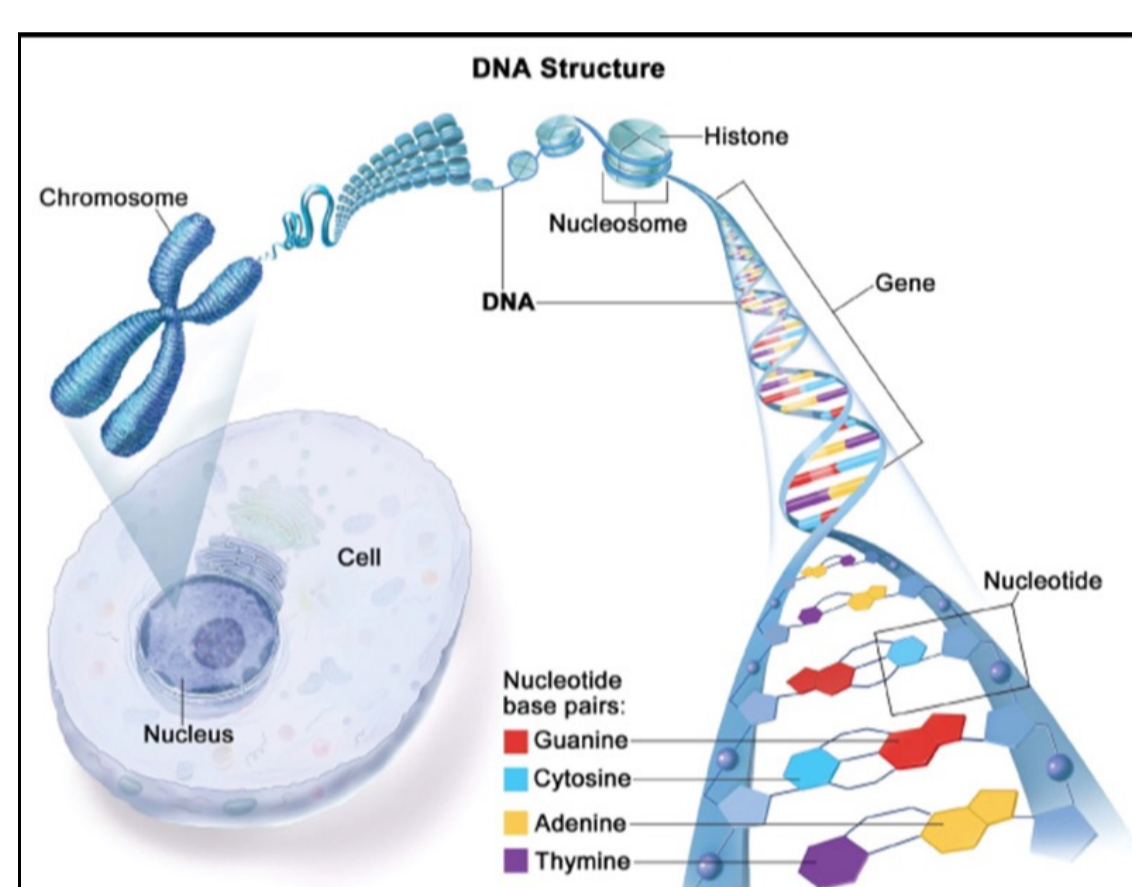


Uplifting Athletes and STXBP1 Foundation Fund \$20,000 Grant to Dr. Noah Guiberson at Weill Cornell Medicine. Read more in this [news post](#).



Rare Disease Day is Coming Soon

Rare Disease day is on February 29th this year and The STXBP1 Foundation will be represented in person at this year's NIH Rare Disease Day. Be sure to join us on social media as we #leap4stxbp1 on this especially rare day! See what we're doing and all the other Rare Disease initiatives around the world in our [event post](#).



The Scientific Director's Corner

Hi everyone! We are starting a new blog series called "The Scientific Director's Corner" authored by James Goss to be published bi-monthly. This series is designed to help our families understand the science behind our research and its potential to change our world. Our first post in the series, Genes Are The Blueprints for Making Proteins, can be read [here](#). In this post, explore the fascinating world of genes with our engaging exploration into the basic components of life. Ever wondered about the inner workings of DNA and how genes shape our biology? Join us as we delve into the science behind inheritance, protein synthesis, and more as we discover the processes of the building blocks of life. As this series progresses, you'll learn about how these processes affect our loved ones and the research we pursue to support them. We hope you enjoy this series!

We're Saving a Seat for You at the STXBP1 Summit+

Reminder...Family Travel Scholarship Applications due on March 1st. Watch for STXBP1 Summit+ registration to open in March. Be sure to reserve your room early, before the rooms at the special rate are sold out!

STXBP1 Summit+ Info [here](#).

Want to participate in the first ever natural history study focused solely on the STXBP1 patient? The purpose of the STARR Natural History Study is to better understand STXBP1-related disorders, and ultimately lead to improved care and treatment. The study is now enrolling at four sites (Children's Hospital of Philadelphia, Children's Hospital Colorado, Weill Cornell Medicine, and Texas Children's Hospital) with a goal to see 100 patients in the first year. To learn more about the study, how to register, and for information on travel reimbursement, go [here](#). If you have any questions, send us an [email](#).

Read our past issues [here](#). We'll see you next month.



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