

Take Home Handout



While handing out this handout to students, you can say, “In today’s class, we’ve talked a lot about rare diseases and how it is like to live with one. Now, there are multiple ways you, as high school students, can be of help. There are things you can do right now as a student in your community and in your future studies, career, or work place. This take-home handout includes some examples and suggestions. I hope you will read through the list and consider doing some of the things suggested there.”

Continue to say something like, “Even very small things can go a long way, like holding the door for someone using a wheelchair or holding a bake sale to raise money for rare disease research. Next time when you see someone on the street or a friend with unusual behavior, before making any judgment, think of the possibility that this person may have an underlying rare disease and that it may be something that’s out of the control of this person.”

At the end of the period, thank the students for their participation and invite any questions from the students. Encourage them to check out the Rare Disease Day website (link provided on the take-home handout), if they have not already done so.

Lastly, we would like to thank you for using this curriculum. We value your feedback. Please contact education@rarediseases.org to let us know what you liked about this curriculum and how we can make it better.

High School Curriculum for Rare Disease Day

Student Take-Home Handout

Things students can do to help in the rare disease community

Some of the things that you, as a high school student, can do now to help:

- Volunteer in a patient support organization
- Tell your family and friends about what you learned today
- Tell others about Rare Disease Day
- Do something if you see someone being bullied
- Stand up for a friend who is being picked on or laughed at
- Hold a fundraising event for rare disease research

Individuals with rare diseases and their family members have shared with us that they would appreciate:

“Just a smile, hold the door for them, make small talk. The small things count more than anything else. Just try to be a real friend.”

“Do not leave these people (those with rare diseases) out of your life. They are very capable of making great friends for life and bless each person they come into contact with. Become aware of their disorder and say hello, invite them to sit with you at lunch, make conversation with them. You just might be surprised that you have something in common.”

“Don’t abandon your friends if they are ill. Just because he/she can’t do everything you do does not mean that they don’t want or need your friendship!”

Professions or jobs that would be helpful for the rare disease community:

Science and Research <ul style="list-style-type: none">• scientist• researcher• lab technician	Health Care <ul style="list-style-type: none">• doctor• nurse• genetic counselor• physical/occupational therapist
Social Services <ul style="list-style-type: none">• patient advocate• social worker• psychologist	Law and politics <ul style="list-style-type: none">• lawyer• politician

Individuals with rare diseases have encouraged high school students with following words:

“Live your life like every day matters. Set goals and don’t wait to achieve them. Don’t forget to let those people who are important to you know that they mean a lot to you. Treat all people with respect. Become actively involved in improving the health care system in our country. Most high school students have to complete community service as part of graduation. Choose a rare disorder and work to bring awareness of that disease to those in your community.”

“Thank you for caring. You are our future, so it’s important that you learn.”

“Study hard in school and one day you may find a cure!”

Remember to visit the Rare Disease Day website: www.rarediseaseday.us