



Debra's Gaisce Award Programme for supporting people with epidermolysis bullosa (EB)

Introduction

Debra aims to inspire young people to become advocates for those living with epidermolysis bullosa (EB). EB is a group of incredibly painful genetic blistering condition that affects the body's largest organ; the skin. People living with EB are missing the essential proteins that bind the skin's layers together, so any minor friction, movement or trauma causes it to break and blister. It's debilitating. Excruciating. Relentless. A disease with no known cure.

There are four main forms of EB that vary in severity, but all carry their own life-limiting symptoms, life-long pain and, in many cases, disability. The more severe forms of EB have a life expectancy range of early infancy to 35 years of age.

EB can affect both, the external and internal lining of the skin.

As a Gaisce Challenge Partner, Debra provides various ideas and resources that can help you achieve the Personal Skill and Community Involvement Challenge Areas for your Gaisce Bronze, Silver, or Gold Award. Whether you want to develop personal skills or make a positive impact in your community, we have plenty of opportunities for you to support people with EB.

13-week plans tailored for you

Based on the requirements and activities from the Gaisce Bronze Award, as well as information from the Debra Gaisce roadmap, here is a 13-week plan for the Personal Skill and Community Involvement areas with a focus on epidermolysis bullosa (EB).

These 13-week plans will help you achieve the necessary activities in each Gaisce Challenge Area while raising awareness and supporting those with EB through your participation in the Debra programme.

Debra will provide guidance and resources to help you succeed in your challenge areas, and we're always here to support you on your Gaisce journey. If you have



any questions or need assistance, please contact Susan (susan.woodcock@debra.ie).

By participating in these activities, you will not only work toward achieving your Gaisce Award, but you will also make a lasting difference for people living with EB in your community.

Personal skill: EB Awareness Challenge (13 weeks)

You can use raising awareness of EB for your Personal Skill Challenge Area. This challenge is not just about improving your understanding of rare diseases like EB, but also about gaining the skills to advocate for those affected by it and their families. It's an opportunity to learn more about how EB impacts people's lives, to foster empathy, and to develop communication and organisational skills through advocacy efforts.

Goal: Learn about EB and advocate for awareness in your community.

Week 1:

- Learn more about EB and rare diseases by reading about the condition or watching documentaries or recordings of people living with the condition (for example: <https://youtu.be/Zvt2N2-mv-k?si=L2vgBcRYYEVUi1Q6>). Use these insights to improve your understanding of the challenges faced by someone with a rare condition.
- Research EB online and watch videos of individuals living with EB (e.g., *Debra Ireland YouTube channel*).
- Begin a journal to document your learning.

Week 2:

- Create an outline for an EB awareness presentation.
- Focus on facts about the condition and how it impacts daily life for those with EB.

Week 3:

- Draft a presentation on EB, highlighting key points to share with your school or community. This can be a way to practise public speaking while educating others about EB.

- Continue documenting your progress and thoughts.

Week 4:

- Practise delivering the presentation to a friend or family member.
- Organise an event at school to share your knowledge of EB.
- Gather feedback for improvement.

Week 5:

- Host an event at school to deliver your EB presentation to a friends and peers.
- Refine based on feedback and update your journal.

Week 6:

- Share EB facts on social media to raise awareness among your peers.
- Consider including infographics or short videos to boost engagement.

Week 7:

- Develop creative skills by creating posters, infographics, or videos to highlight the experiences of people with EB and how communities can offer support and share it at school or with your friends.
- Begin planning for a community awareness event or activity.

Week 8:

- Deliver your EB presentation at a local community centre.
- Reflect on the experience and how you can improve future advocacy efforts.

Week 9:

- Research policies and healthcare services for rare diseases like EB.
- Create a list of gaps or areas where you think more support is needed.

Week 10:

- Continue your journal, and update it with your research findings on healthcare policies.
- Engage in research and advocacy by staying informed about policies and healthcare services available for those with EB and rare diseases and create ways to influence local change.



- Share information and raise awareness about EB to your friends using social media, explaining what it is and why it's important to support those affected.

Week 11:

- Engage with Debra on social media to see how their advocacy aligns with your findings.
- Write an article or blog post about your experience learning about EB and how people can help.
- Submit the post to a local newsletter or community site.

Week 12:

- Share your blog post or article on your social media platforms to further raise awareness.

Week 13:

- Prepare a summary of your journey in EB advocacy and submit it to Debra to inspire others.

Community Involvement: Supporting the EB Community (13 weeks)

Community Involvement is an opportunity to make a tangible difference for people with EB and their families. EB is often called “the worst disease you’ve never heard of,” and this is your chance to help change that by raising awareness, supporting fundraising efforts, or directly engaging with people living with the condition.

Goal: Create a supportive environment for people with EB through community efforts.

Week 1:

- Form a ‘Friends of Debra’ group in your school and assign roles (e.g., Chairperson, Treasurer, Secretary). Work with friends to support Debra’s goals by raising awareness and organising events that engage your community or raise funds.

Week 2:

- Organise an initial meeting with your group to plan awareness and fundraising activities.
- Plan an EB awareness event such as a school assembly or coffee morning.

Week 3:

- Host a small EB awareness event in your school or community, sharing facts about EB. You could organise a school assembly, information evening, or coffee morning where you share facts about EB and the challenges faced by individuals and families affected by the condition.

Week 4:

- Start planning a fundraising activity for Debra. You could host a bake sale, sports day, or quiz night, raising funds to support Debra Ireland's vital work in supporting people living with EB.
- Reach out to local companies to sponsor an event or donate prizes for fundraising activities in support of Debra.

Week 5:

- Finalise details for your fundraising event and promote it through posters and social media.

Week 6:

- Host your fundraising event and raise funds for Debra or volunteer at a Debra event – Debra organises fundraising events such as walks, runs, and charity days. You can volunteer at one of these events, helping with registration, promotion, or logistics.
- Reflect on what worked well and what could be improved for future events.

Week 7:

- Reach out to a local primary school and offer to start a Buddy Support Programme, promoting empathy for those with disabilities.

Week 8:

- Begin the Buddy Support Programme, working with younger students to promote inclusion.

Week 9:

- Plan a local EB information evening and invite your community to attend.
- Partner with a local business or organisation to sponsor the event.

Week 10:

- Execute the information evening and collect feedback from attendees.
- Create a mural or artwork that symbolises hope and support for people with EB. You could work with your local community to display it in a prominent place.

Week 11:

- Work with your group to create educational materials about EB, such as leaflets or posters, to distribute in your local community.
- Start a campaign to share facts about EB and encourage your friends and community to support Debra Ireland through donations or participation in events.

Week 12:

- Visit Debra's office to learn more about their daily work.
- Run a storytelling campaign – Highlight personal stories of individuals living with EB, either through interviews or by sharing stories already published by Debra, to bring a personal touch to your advocacy.

Week 13:

- Complete a reflection on how your community efforts have made an impact and share your story with Debra.