














The Challenges we face	What we do	The change we contribute to	Our Ultimate Goal
<p>People with EB live in pain and discomfort, affecting their ability to fully participate in every aspect of life. They and their families are burdened with stress and anxiety and feelings of isolation, which have a negative effect on their wellbeing.</p>	<p>Provide support for families living with EB including helping with access to services and providing opportunities for respite and connection with others in similar situations.</p>	<p>Wellbeing</p> <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Families feel supported </div> <div style="text-align: center;">  Families feel connected </div> <div style="text-align: center;">  People with EB feel more independent </div> <div style="text-align: center;">  Wellbeing increases </div> </div>	<p>Every person living with EB has access to the same level of improved care and financial support. Families who live with EB have greater opportunity to be families and participate in life to its fullest. People living with EB are celebrated and included in society.</p> <p>There are advances in treatment and prevention that mean that there are less people born with EB, and those that live with EB can live a life free of pain and itching.</p>
<p>Knowledge of EB among health professionals is limited. There is inequity of access to the best possible care for people with EB.</p>	<p>Providing funding and advocating for clinical services.</p> <p>Providing opportunities for health professionals to share knowledge.</p>	<p>Treatment Today</p> <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Health professionals have increased knowledge of EB </div> <div style="text-align: center;">  The healthcare system has increased capacity to treat EB </div> <div style="text-align: center;">  People with EB have increased access to treatment </div> </div>	
<p>There is currently no cure for EB, and further research into prevention, and treating the more serious of symptoms of EB, is required.</p>	<p>Providing funding for research, and opportunities for collaboration.</p>	<p>Treatment Tomorrow</p> <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Increased knowledge sharing amongst researchers and health professionals </div> <div style="text-align: center;">  Growing networks of EB researchers </div> <div style="text-align: center;">  Faster translation of research into practice </div> </div>	
<p>Living with EB is costly, and puts financial pressure on people with EB, families and carers. Due to its rarity, there is a lack of awareness in the community about EB, and limited financial support for people with EB and their families.</p>	<p>Raising awareness of EB through fundraising and advocacy activities.</p>	<p>Awareness</p> <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="text-align: center;">  Increased awareness of EB </div> <div style="text-align: center;">  Increased funding and advocacy for people with EB </div> <div style="text-align: center;">  More resources available to support wellbeing and treatment </div> </div>	