

MEETING AIMS:

- Explore the potential of strategic alliances and social media to increase the efficacy and sustainability of heart failure organisations;
- Gain insight into the needs of carers and how best to meet their needs;
- Discuss ways in which groups can work together to secure more attention for heart failure and put heart failure on the health policy agenda;
- Provide heart failure patient groups leaders the opportunity to network and learn from each other.

DAY 1

Time	Duration	Topic & Presenter/Moderator
08.30-08.40	10min	Welcome & opening remarks Presenter: Neil Johnson, CEO Croí, Ireland
08.40-09.00	20min	Meeting overview, ground rules and introductions Moderator: Kathy Redmond, Redmond Consulting, Switzerland
09:00-09:45	45 min	<i>The networked patient group: Using social media to increase reach and influence</i> Presenter: Denis Costello, EURORDIS – Rare Diseases Europe, Spain 30-minute presentation and 15 minutes discussion/Q&A
09.45-10.45	60 min	<i>Learning from each other: Examples of best practice in the heart failure setting</i> <ul style="list-style-type: none"> • Daniela Briones- iHHub • Marc Bains – The Heartlife Foundation • Patricia Vlassman – Let the beat go on/Heart4Research • Patricia Hall – Irish Heart Foundation • Rozalina Lapadatu - IDSE Moderator: Kathy Redmond
10.45-11.15	30 min	Coffee Break and poster viewing
11.15-12:00	45 min	<i>Alliance building – the road to more sustainable and effective patient advocacy</i> Presenter: Donna Walsh, Executive Director, EFNA, Ireland
12:00-12:45	45 min	<i>Putting heart failure on the health policy agenda: What can be learnt from other disease areas?</i> Panel discussion with Denis Costello & Donna Walsh Moderator: Kathy Redmond
12:45-13:45	60 min	Lunch and poster viewing
13:45-15:15	90 min	<i>World Café: Putting heart failure on the health policy agenda</i> 4-5 tables moderated by selected heart failure advocates

Time	Duration	Topic & Presenter/Moderator
15:15-15:45	30 min	Feedback from World Café and consensus on how to put heart failure on the health policy agenda Moderator: Kathy Redmond
15:45-16:00	15 min	Day 1 Summary Presenter: Neil Johnson, CEO Croí
16:30		Walking tour of Galway city

DAY 2

Time	Duration	Topic & Presenter/Moderator
08.30-08.35	5 min	Introduction to day 2 Presenter: Neil Johnson, CEO Croí, Ireland
08:35-09:20	45 min	Caring for carers: Challenges and solutions Presenter: Liam O'Sullivan, Executive Director, Care Alliance Ireland
09:20-10:30	70 min	Learning from each other: Examples of best practice in meeting the needs of Heart Failure patients and their carers <ul style="list-style-type: none"> • Anne Kihlman-Kitinjoja - South Finland's Heart District • Winfred Klausnitzer - Herzschaeweche Franken e.V. • Inese Maurina – Parsirdi • Ellen Ross – Heart and Stroke Foundation • Joel Ross – Cardiomyopathy UK • Maite San Saturnino – Cardioalanza <p>Moderator: Kathy Redmond</p>
10:30-11:00	30 min	Coffee Break
11.00-11:45	45 min	Alliance building: working together to strengthen the heart failure community 4-5 tables moderated by selected heart failure advocates
11:45-12:15	30 min	Feedback from the groups and consensus on potential collaborative initiatives Moderator: Kathy Redmond
12:15-12:30	15 min	Meeting close and next steps Presenter: Neil Johnson, CEO Croí, Ireland
12:30-13:30		Lunch