



# Spina Bifida Hydrocephalus Ireland

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George Kennedy, CEO, SBHI

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# SBHI's Vision

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That people with Spina Bifida and/or Hydrocephalus will participate to their fullest potential in all aspects of life

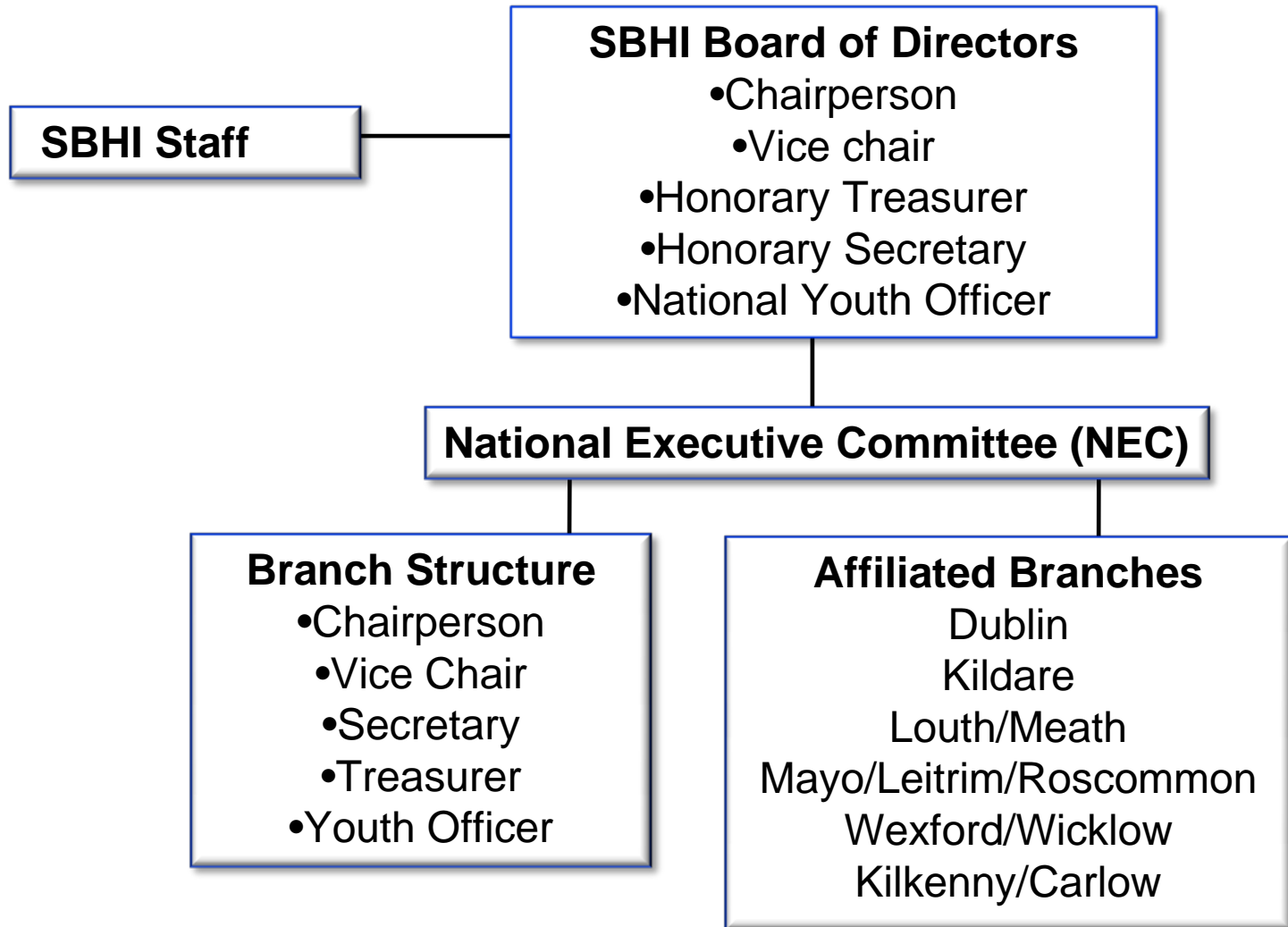


# SBHI's Mission Statement

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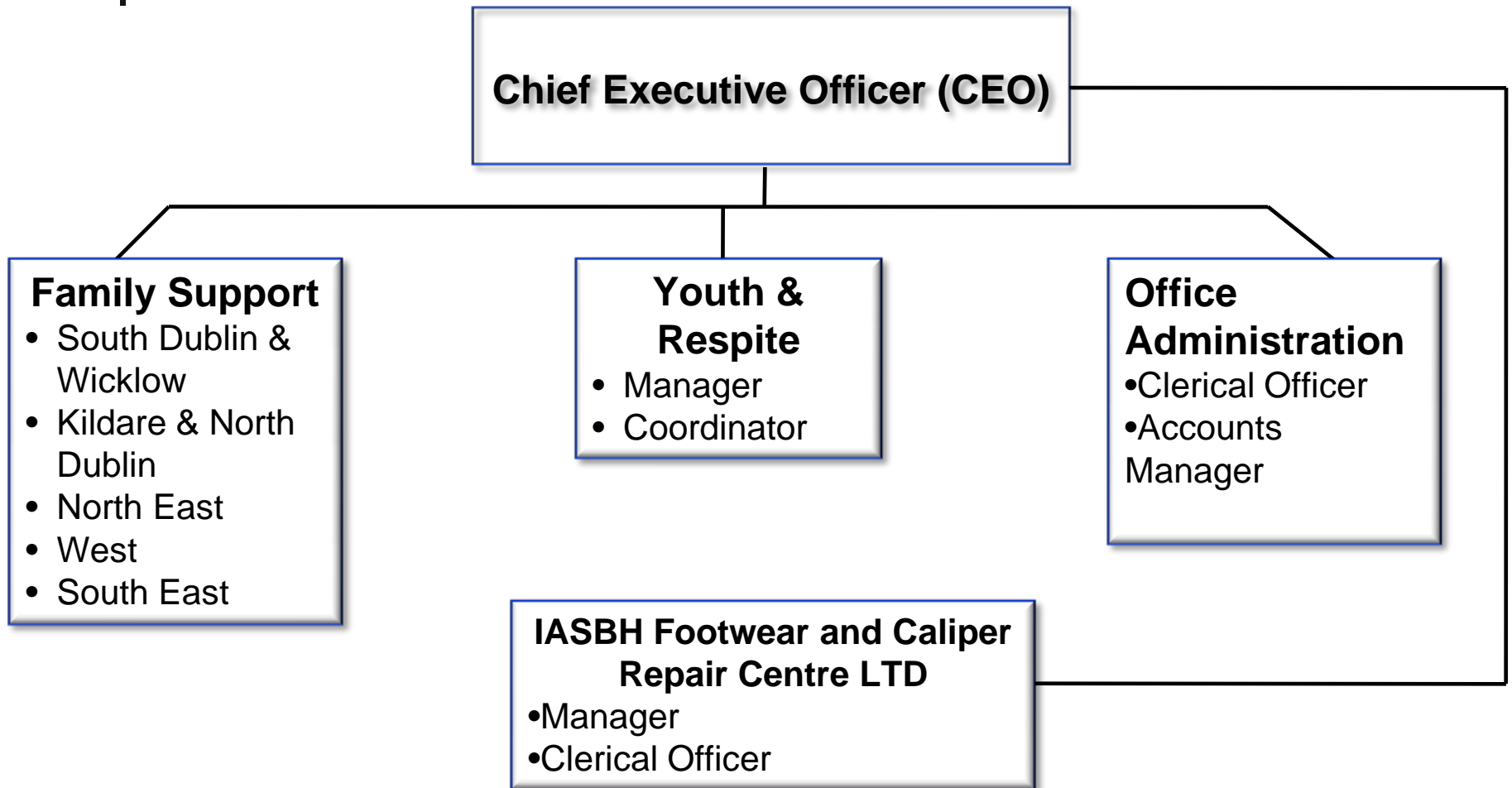
- To provide information, support and advice to people with Spina Bifida and/or Hydrocephalus, their parents, carers and siblings.
- To promote social inclusion and equality for people with Spina Bifida and/or Hydrocephalus in Irish society.

# Structure





# Staff Structure





# Family Support Services

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- The Family Support team come from a range of backgrounds such as nursing, education and social care.
- The role of the family Support Worker is very diverse and is guided by the needs of our service users, their families and carers.
- Our aim is to provide guidance, advocacy, emotional and practical support.
- There are frequent outreach support groups for members, parents/carers within all our regions.



# Family Support Services cont'd

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- Our FSWs liaise with professionals from: nursing, midwifery, paediatric, social work, OT, physio, early intervention and hospitals to ensure that our members receive the best possible provisions and support that they require.
- A FSW will visit the member while at home, school, college, work or hospital.
- Information and support on issues with education, housing, entitlements, advocacy, employment, social needs.

# Family Support Services cont'd

- FSW team organise and run seminars annually to inform and educate members, parents/carers and also professionals working with these conditions.
- Family Weekends
- Sometimes all that our service users need is someone to listen to them. *This is also an essential part of the Family Support Workers' role.*

# Youth & Respite Services

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- SHINE (summer project)
- Weekend getaways and mid-term breaks in different venues throughout the year for adults & teenagers
- Sports Adventure week annually for those service users who are outdoor sports enthusiasts or like a challenge
- National Sports Fun Day
- Youth Forum run nationwide by members (supported by staff in NRC) eg sports activities, educational fora, employment fora etc
- Youth Café for teenagers with and without disabilities in different venues in Dublin, Kildare and Wicklow in conjunction with IWA – to be piloted and confirmed
- Seasonal events eg Valentine, Easter, Halloween



# Youth & Respite Services

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- Support, backup and input into all conference, seminars, family weekends etc with relevance to the youth section of SBHI
- Input for the relevant sections of communication tools used by SBHI to inform members
- Enhancing the profile of SBHI in all relevant national youth organisations
- Recruit, select and provide training for volunteers and staff for various projects organised by SBHI (particularly for SHINE)



# Continence Advisory Service

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- To inform and advise the service user on the condition and assist them with their challenges
- Runs information sessions throughout Ireland to individuals with Spina Bifida, parents/carers and professionals
- Phone consultation 01-4572329



# Senior OT -Hydrocephalus

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- Specializes in Hydrocephalus
  - Assesses the individuals on a one-to-one basis
  - Plans programme(s)
  - Aids with the implementation of programme(s) with regular contact if required
  - Liaises with other professionals
  - Runs information sessions for professionals throughout Ireland
  - Contact through 01-4572329



# Footwear & Calliper Centre

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- Established in the mid 1980s
- Enables members to acquire suitable orthopaedic footwear and appliances
- Caters for all aspects of orthopaedic footwear e.g. sports injuries, fashionable orthopaedic shoes for children
- Repair service
- Regular clinics
- A fully trained Orthotist is always in attendance at all clinics
- Contact 01-4572326



# Communications

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- Information leaflets
- Calendar of Events
- Seminars
- Spina Bifida Clinic
- Ability Magazine
- Various workshops and educational programmes
- Website: [www.sbhi.ie](http://www.sbhi.ie)
- Telephone: National Resource Centre 01-4572329



# Some Upcoming Events

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- Mid Term Activity Break (Teenagers), SHARE Holiday Centre, Fermanagh 27<sup>th</sup> – 30<sup>th</sup> Oct
- Halloween Party, 29<sup>th</sup> Oct, Roadstone Social Club, Kingswood, Dublin 22
- Weekend Getaway (Adults), Kilcuan Centre, Clarinbridge, Co. Galway, 6<sup>th</sup> – 9<sup>th</sup> Nov
- Family Weekend, 27<sup>th</sup> – 29<sup>th</sup> Nov, Cuisle, Co. Roscommon



# Some Upcoming Events

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- Superstars Bowling League (Adults) – every Wednesday, Tallaght Leisureplex, examining the possibility of extending this to other parts of the country
- Series of other events – for further info contact SBHI