

**SUPPLEMENTARY FILE 4**

A list of invited patient support groups for the Delphi survey

<b>Name of Society</b>
Hidradenitis Patiëntenvereniging (NL)
Nevus Netwerk Nederland (NL)
Nevus Outreach (US)
Nevus Support (AU)
Neurofibromatose Vereniging Nederland (NL)
The Neuro Foundation (UK)
Neurofibromatose Ireland Association (IE)
Vereniging Wijnvlek Sturgeweber syndroom (NL)
Schweizerischen Nuerofibromatose Vereinigung (CH)
Interessengemeinschaf Sturge-Weber-Syndrom (DE)
Sturge Weber Foundation Great Britain (UK)
Sturge-Weber-Foundation (US)
Vitiligo patientenvereniging (NL)
National Vitiligo Foundation (US)