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**Table SI. Objectives of MDHHgermany**

- Establishment of evidence-based clinical registry and research network
- characterisation of medical care and pharmaceutical therapies for DD and HHD patients
- gathering patient perspectives on disease-related quality of life, treatment goals, treatment satisfaction and treatment sequence
- evaluation of the effectiveness, safety and tolerability of topical and systemic therapies for DD and HHD
- establishment of a foundation for further research, such as clinical trials, epidemiological studies, and immunological investigations to improve the quality of life of these patients.

**Table SII. Structure of the questionnaire at V1 in the MDHHgermany registry (questionnaire can be downloaded here: [https:// bit. ly/ 3efDR uM](https://bit.ly/3efDRuM))**

<b>Baseline visit (V1)</b>	
<b>Demographics</b>	<ul style="list-style-type: none"> <li>• Sex</li> <li>• Age at inclusion and at disease onset</li> <li>• Weight</li> <li>• Height</li> <li>• Education status</li> <li>• Employment status and absence from work</li> <li>• Marital status</li> <li>• Parental status</li> </ul>
<b>Familial and personal disease history</b>	<ul style="list-style-type: none"> <li>• year of primary diagnosis</li> <li>• affection within family and disease severity</li> <li>• disease severity progression</li> <li>• inpatient stays within last 5 years</li> <li>• outpatient consultations within last 12 months</li> <li>• reason for physician visits</li> <li>• alternative practitioners visits</li> </ul>
<b>Severity of disease</b>	<ul style="list-style-type: none"> <li>• Self-evaluation of disease severity, using scale from "no disease activity" to "severe affection."</li> <li>• Relevance of 10 predefined subjective symptoms</li> <li>• satisfaction with treatment and medical care during past three months on a 10-point-scale</li> <li>• assessment of disease severity, pain, pruritus, burning sensation, sleep disturbance within the last 3 days on a 0- to 10-point-scale (numeric rating scale)</li> <li>• reflection of disease control within last 12 months</li> </ul>
<b>Recent therapies and treatment goals</b>	<ul style="list-style-type: none"> <li>• relevance of 10 predefined treatment goals</li> <li>• possibility for participation in treatment decision</li> <li>• satisfaction with treating physician</li> <li>• systemic and topical therapies since disease onset</li> <li>• personal assessment of the most tolerable and effective systemic and topic treatment</li> <li>• expenses per month in Euros</li> </ul>
<b>Mental burden</b>	<ul style="list-style-type: none"> <li>• quality of life (DLQI)</li> <li>• subjective well-being</li> <li>• overall satisfaction of life</li> </ul>