

Additional table 1. Additional characteristics of the informal caregivers

| | N=77 |
|--|-------------|
| Handicap financial allocation | 64 (83.1) |
| Housing fitting out allocation | 7 (9) |
| Human assistance at home | 15 (19.5) |
| Technical assistance allocation | 39 (50.6) |
| Psychologist/psychiatric contact | 17 (22.1) |
| Social worker contact | 33 (42.9) |
| Handicap association Contact | 20 (26.7) |
| Satisfaction about the care support | 30 (40.3) |
| Satisfaction with the medical information delivery | 29 (37.7) |
| Family's contact preservation | 69 (89.5) |
| Leisure preservation | 29 (37.7) |
| Holidays preservation | 34 (44.2) |

Additional table 2. Relationships between self-perceived burden of caregivers and the neurodevelopmental and functional status of PLH children

| | | Self- esteem [0-100]* | Familial support [0-100]** | Financial [0-100]** | Planifi- cation [0-100]** | Health [0-100]** |
|--|---------|--------------------------------------|---|--------------------------------|--|-----------------------------|
| Neurodevelopment status[°] | | | | | | |
| Language | R | -0.055 | -0.199 | 0.193 | -0.115 | 0.066 |
| | p-value | 0.656 | 0.109 | 0.114 | 0.354 | 0.596 |
| Posture-motor ability | R | 0.017 | -0.073 | 0.239 | -0.053 | 0.059 |
| | p-value | 0.890 | 0.562 | 0.050 | 0.671 | 0.634 |
| Coordination | R | 0.042 | -0.184 | 0.183 | -0.142 | 0.059 |
| | p-value | 0.744 | 0.157 | 0.151 | 0.271 | 0.648 |
| Sociability | R | -0.250 | -0.048 | 0.252 | -0.055 | 0.070 |
| | p-value | 0.063 | 0.729 | 0.061 | 0.688 | 0.611 |
| Functional indices^{°°} | | | | | | |
| Orthopedic index [0-5] | R | -0.053 | 0.434** | 0.108 | 0.262* | 0.295* |
| | p-value | 0.654 | <0.001 | 0.363 | 0.026 | 0.012 |
| Respiratory index [0-5] | R | 0.041 | 0.150 | 0.183 | 0.257* | 0.183 |
| | p-value | 0.734 | 0.214 | 0.123 | 0.031 | 0.127 |
| Digestive index[0-4] | R | 0.054 | 0.264* | 0.168 | 0.099 | 0.263* |
| | p-value | 0.647 | 0.026 | 0.156 | 0.410 | 0.025 |
| Urologic index [0-3] | R | 0.213 | 0.240* | 0.108 | 0.192 | -0.027 |
| | p-value | 0.072 | 0.045 | 0.368 | 0.109 | 0.820 |
| Pain index [0-4] | R | 0.094 | 0.292* | -0.155 | 0.208 | 0.131 |
| | p-value | 0.427 | 0.013 | 0.191 | 0.080 | 0.273 |
| Skin index [0-6] | R | 0.260* | 0.239* | -0.024 | 0.120 | 0.076 |
| | p-value | 0.027 | 0.045 | 0.839 | 0.313 | 0.528 |
| Sleep disorders index [0-4] | R | 0.083 | 0.206 | 0.096 | 0.258* | 0.154 |
| | p-value | 0.491 | 0.089 | 0.427 | 0.031 | 0.203 |

* 100: best self-esteem, ** 100: worse familial support, worse financial impact, worse planification impact, worse health impact

[°] Neurodevelopmental status levels range from 0 to 24 months

^{°°} Higher scores: higher level of organ disorders

Bold values: p-value <0.05

Additional table 3. Factors associating with caregivers' self-perceived burden of parents' (using Generalized Estimating Equations models)

| | | <i>Self-esteem</i> | | Familial support* | | Financial* | | Planification* | | Health* | |
|--|---------------------|--------------------|--------------|-------------------|--------------|------------|--------------|----------------|--------------|---------|--------------|
| | | β | p-value | β | p-value | β | p-value | β | p-value | β | p-value |
| 1. Caregivers' variables | | | | | | | | | | | |
| Age of the parent | | | | | | 0.323 | 0.192 | | | 0.043 | 0.839 |
| Other person with disability at home (0 no, 1 yes) | | -5.365 | 0,253 | | | -10.48 | 0.015 | | | | |
| Financial status (0 not difficult, 1 difficult) | | | | | | -9.164 | 0.112 | | | | |
| Chronic disease (0 no, 1 yes) | | | | | | -5.390 | 0.364 | | | -9.251 | 0.014 |
| Hospitalization episode (0 no, 1 yes) | | -6,203 | 0,085 | | | | | -5.564 | 0.216 | | |
| Quality of life | Physical | -0.158 | 0.226 | -0.394 | 0.019 | -0.191 | 0.168 | -0.354 | 0.005 | | |
| | Psychological | 0.033 | 0.811 | 0.137 | 0.561 | 0.379 | 0.027 | 0.360 | 0.011 | | |
| | Social | 0.039 | 0.749 | 0.104 | 0.424 | -0.212 | 0.039 | 0.143 | 0.103 | | |
| | Environ. | -0.096 | 0.529 | -0.345 | 0.042 | -0.266 | 0.128 | -0.394 | 0.003 | | |
| Anxiety-mood score | | 1.130 | 0.130 | | | | | 0.858 | 0.237 | | 0.044 |
| Coping | Social support | -0.265 | 0.002 | | | | | | | | |
| | Avoidance | | | | | | | -0.006 | 0.975 | 0.116 | 0.436 |
| | Positive thinking | | | | | -0.051 | 0.659 | | | | |
| Daily time caregiving | (0: <=4h, 1: [5-8]) | -0.997 | 0.845 | | | | | -7.346 | 0.133 | | |
| | (0: <=4h, 2: >=9) | -4.602 | 0.257 | | | | | 0.275 | 0.943 | | |
| Get up during night (0: <2, 1: >=2) | | -9.711 | 0.005 | | | | | -8.819 | 0.025 | -5.815 | 0.048 |
| 2. PLH individuals' variables | | | | | | | | | | | |
| Gender of the PLH individual (0 boy/man, 1 girl/woman) | | 4.680 | 0.201 | | | | | | | | |
| Age of the PLH individual | | 0.809 | 0.010 | | | | | | | 1.208 | 0.015 |

β beta standardized coefficient; Bold values: p-value <0.05

* higher scores, worse burden