Supplemental Tables

Table S1 Additional details of the qualitative interviews

| Study organizational structure                                      |
|---------------------------------------------------------------------|
| The study was conducted by the sponsor (Actelion) in collaboration  |
| with a contract research organization (Evidera)                    |

| Researchers                                                         |
|---------------------------------------------------------------------|
| Two female health outcomes research professionals (LS and SS),     |
| each with a master’s degree and with training and experience in    |
| conducting qualitative interviews                                   |

| Process                                                             |
|---------------------------------------------------------------------|
| The study sites provided the researchers with contact information  |
| for eligible patients who were willing to participate              |
| One of the researchers (SS) then contacted potential participants   |
| by telephone to schedule the interviews                             |
| At the beginning of the interview, the researcher conducting the   |
| interview (LS or SS) introduced herself by name to participants,   |
| and provided her employer’s name (Evidera) and the reason for      |
| doing the interviews                                               |
| Audio files were transcribed verbatim by a transcription vendor,   |
| Gordon Transcripts                                                 |
| The final “cleaned” transcripts were not returned to participants  |
| for comment or correction                                           |

| Analysis                                                            |
|---------------------------------------------------------------------|
| A coding framework was developed by one researcher (LS) using the   |
| main concepts included in the interview guide                       |
| The coding framework was revised based on findings from the early  |
| interviews                                                          |
| Using the resulting coding dictionary, two researchers (LS and SS)  |
| independently coded one transcript                                   |
| The dual-coded transcript was reviewed to confirm that the         |
| researchers had captured all relevant responses and were           |
| interpreting and using codes consistently and as intended. The     |
| remaining transcripts were then coded by one of the researchers (SS)|
| and the other researcher (LS) checked the quality of the coded     |
| transcripts                                                         |
| All quantitative data were collected using DataFax (DF/Net Research,|
| Inc., Seattle, WA), an optical character recognition software      |
| package that is compliant with Part 11 of Title 21 of the US Food  |
| and Drug Administration Code of Federal Regulations                 |
### Table S2 Saturation grid for symptom concepts

| Symptom Concept                                  | First (transcripts 1 and 2) | Second (transcripts 3 to 5) | Third (transcripts 6 to 8) | Fourth (transcripts 9 to 11) | All transcripts (N=11) |
|--------------------------------------------------|-----------------------------|-----------------------------|---------------------------|-----------------------------|-----------------------|
|                                                  | n                           | n                           | n                         | n                           | n (%)                 |
| Shortness of breath                              | 2                           | 3                           | 3                         | 3                           | 11 (100)              |
| Swelling in ankles or legs                       | 2                           | 3                           | 3                         | 3                           | 11 (100)              |
| Fatigue                                          | 2                           | 2                           | 3                         | 3                           | 10 (91)               |
| Lack of energy                                   | 1                           | 2                           | 3                         | 3                           | 9 (82)                |
| Cough                                            | 1                           | 2                           | 3                         | 3                           | 9 (82)                |
| Rapid heartbeat                                  | 2                           | 2                           | 3                         | 2                           | 9 (82)                |
| Wheezing                                         | 2                           | 1                           | 3                         | 3                           | 9 (82)                |
| Skin issues                                      | 2                           | 2                           | 3                         | 2                           | 9 (82)                |
| Chest pain                                       | 1                           | 1                           | 3                         | 3                           | 8 (73)                |
| Lightheadedness                                  | 2                           | 1                           | 2                         | 3                           | 8 (73)                |
| Eye issues                                       | 2                           | 1                           | 3                         | 2                           | 8 (73)                |
| Non-chest pain                                   | 1                           | 1                           | 2                         | 3                           | 7 (64)                |
| Chest tightness                                  | 1                           | 2                           | 1                         | 2                           | 6 (55)                |
| Swelling in stomach area                         | 1                           | 1                           | 1                         | 0                           | 3 (27)                |
| Balance issues                                   | 1                           | 0                           | 0                         | 0                           | 1 (9)                 |
| Legs feeling like they will “give out”           | 1                           | 0                           | 0                         | 0                           | 1 (9)                 |
| Numbness in fingers                              | 1                           | 0                           | 0                         | 0                           | 1 (9)                 |
| Problems urinating (attributed to sarcoidosis in kidneys) | 1                           | 0                           | 0                         | 0                           | 1 (9)                 |
| Seizures and Bell’s palsy symptoms (attributed to sarcoidosis in the brain and stress) | 1                           | 0                           | 0                         | 0                           | 1 (9)                 |
| Swelling in hands                                | 1                           | 0                           | 0                         | 0                           | 1 (9)                 |
| Heart palpitations                               | 0                           | 2                           | 3                         | 2                           | 7 (64)                |
| Headache                                         | 0                           | 1                           | 2                         | 0                           | 3 (27)                |
| Heavy feeling in the chest or pressure on the chest (different than tightness or pain) | 0                           | 1                           | 0                         | 0                           | 1 (9)                 |
| Weakness (general)a                              | 0                           | 0                           | 1                         | 0                           | 1 (9)                 |
| Weakness and pain in handsa                      | 0                           | 0                           | 0                         | 1                           | 1 (9)                 |
| Left side of body feels different (feels “not good”)a | 0                           | 0                           | 0                         | 1                           | 1 (9)                 |
| Congestion; lump in throat (needing to clear throat)a | 0                           | 0                           | 0                         | 1                           | 1 (9)                 |

Numbers represent the number of participants within each transcript group who raised or endorsed a particular symptom concept spontaneously or upon probing.

*a* It was judged that these concepts overlapped with concepts that had been raised or endorsed by earlier transcript groups or were likely related to other health conditions.
### Table S3 Saturation grid for impact concepts

| Impact concept                                        | First (transcripts 1 and 2) n | Second (transcripts 3 to 5) n | Third (transcripts 6 to 8) n | Fourth (transcripts 9 to 11) n | All transcripts (N=11) n (%) |
|-------------------------------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|
| Difficulty walking up stairs                          | 2                             | 3                             | 3                             | 3                             | 11 (100)                      |
| Ability to walk (general)                              | 2                             | 2                             | 3                             | 3                             | 10 (91)                       |
| Carrying things                                       | 2                             | 2                             | 3                             | 3                             | 10 (91)                       |
| Housework                                             | 2                             | 2                             | 3                             | 3                             | 10 (91)                       |
| Difficulty with hills                                 | 1                             | 2                             | 3                             | 3                             | 9 (82)                        |
| Hobbies                                               | 1                             | 2                             | 3                             | 3                             | 9 (82)                        |
| Oxygen use                                            | 2                             | 2                             | 2                             | 2                             | 8 (73)                        |
| Work/school/volunteering                              | 2                             | 1                             | 2                             | 3                             | 8 (73)                        |
| Other daily activities                                | 2                             | 2                             | 1                             | 2                             | 7 (64)                        |
| Self-care activities                                  | 1                             | 1                             | 2                             | 3                             | 7 (64)                        |
| Mental functioning                                    | 2                             | 1                             | 2                             | 2                             | 7 (64)                        |
| Dependence on others                                  | 1                             | 2                             | 2                             | 2                             | 7 (64)                        |
| Sleep impacted                                        | 1                             | 3                             | 1                             | 2                             | 7 (64)                        |
| Running or exercise                                   | 1                             | 2                             | 2                             | 1                             | 6 (55)                        |
| Walking quickly                                       | 2                             | 2                             | 1                             | 0                             | 5 (45)                        |
| Walking slowly                                        | 2                             | 1                             | 1                             | 1                             | 5 (45)                        |
| Feeling frustrated or angry                           | 2                             | 1                             | 1                             | 1                             | 5 (45)                        |
| Feeling worried or anxiety                            | 1                             | 1                             | 1                             | 1                             | 4 (36)                        |
| Feeling sad or depression                             | 1                             | 1                             | 1                             | 1                             | 4 (36)                        |
| Driving                                               | 1                             | 1                             | 0                             | 1                             | 3 (27)                        |
| Feeling embarrassed                                   | 1                             | 0                             | 1                             | 1                             | 3 (27)                        |
| Parenting or family impact                            | 2                             | 0                             | 1                             | 0                             | 3 (27)                        |
| Running errands/shopping                              | 1                             | 0                             | 0                             | 1                             | 2 (18)                        |
| Clothing or shoe fit from swelling                    | 1                             | 0                             | 0                             | 1                             | 2 (18)                        |
| Impact of knowing you will never be healthy           | 0                             | 1                             | 0                             | 0                             | 1 (9)                         |
| Talking or singing impacted                           | 0                             | 0                             | 1                             | 1                             | 2 (18)                        |
| Bone issues (fragile, "dead bone")                   | 0                             | 0                             | 1                             | 1                             | 2 (18)                        |
| Social activities                                     | 0                             | 0                             | 1                             | 0                             | 1 (9)                         |
| Weight loss                                           | 0                             | 0                             | 1                             | 0                             | 1 (9)                         |
| Incontinence                                          | 0                             | 0                             | 1                             | 0                             | 1 (9)                         |

Numbers represent the number of participants within each transcript group who raised or endorsed a particular impact concept spontaneously or upon probing.