### Supplementary Table S1. General descriptive statistics (n = 85)

| Variable                        | Min. | Max. | Mean | SD   |
|---------------------------------|------|------|------|------|
| Cantril – today                 | 7.39 | 1.59 | 3.0  | 10.0 |
| Cantril – next 4 weeks          | 7.80 | 1.51 | 4.0  | 10.0 |
| SWLS                            | 24.74| 4.95 | 13.0 | 35.0 |
| HADS-M ANXIETY                  | 0.0  | 17.0 | 5.47 | 4.06 |
| HADS-M DEPRESSION               | 0.0  | 9.0  | 2.99 | 2.94 |
| HADS-M RAGE                     | 0    | 6    | 2.59 | 1.58 |
| STAI – state                    | 36.36| 12.12| 20.0 | 63.0 |
| STAI – trait                    | 39.19| 10.05| 20.0 | 62.0 |
| GQL – Global health status      | 25   | 100  | 73.63| 17.15|
| NV – Nausea and vomiting        | 0    | 66.67| 5.49 | 12.17|
| P – Pain                        | 0    | 100  | 25.49| 23.37|
| D – Dyspnoea                    | 0    | 66.67| 9.02 | 18.10|
| S – Insomnia                    | 0    | 100  | 30.59| 30.52|
| A – Appetite loss               | 0    | 66.67| 10.98| 18.10|
| C – Constipation                | 0    | 66.67| 9.02 | 18.82|
| DIA – Diarrhoea                 | 0    | 100  | 27.06| 31.49|
| FIN – Financial difficulties    | 0    | 100  | 6.27 | 18.18|
| PF1 – Physical functioning      | 26.67| 100  | 84.94| 15.12|
| RF1 – Role functioning          | 0    | 100  | 81.57| 23.99|
| CFI – Cognitive functioning     | 0    | 100  | 81.18| 20.22|
| EFI – Emotional functioning     | 0    | 100  | 77.16| 21.33|
| SF1 – Social functioning        | 0    | 100  | 88.04| 20.02|

### Supplementary Table S2. Gender differences in questionnaires’ results

| Variable                        | Mean rank – men | Quartiles – men | Mean rank – women | Quartiles – women | U-Mann Whitney test of group differences |
|---------------------------------|-----------------|-----------------|-------------------|-------------------|------------------------------------------|
| Cantril – today                | 45.63           | 7.00 8.00 8.00  | 41.71             | 6.00 8.00 8.00   | −0.71; n.s.                               |
| Cantril – next 4 weeks         | 38.88           | 7.00 8.00 8.00  | 45.03             | 7.00 8.00 9.00   | −1.11; n.s.                               |
| SWLS                            | 43.18           | 22.25 25.00 28.75 | 42.91             | 22.00 25.00 28.50| −0.05; n.s.                               |
| HADS-M ANXIETY                 | 37.14           | 1.00 4.00 7.75  | 45.88             | 3.00 4.00 9.00   | −1.54; n.s.                               |
| HADS-M DEPRESSION              | 46.66           | 0.25 2.50 6.50  | 41.20             | 0.00 2.00 5.00   | −0.97; n.s.                               |
| HADS-M RAGE                    | 40.36           | 1.25 2.50 3.00  | 44.30             | 1.50 3.00 4.00   | −0.71; n.s.                               |
| STAI – state                   | 36.79           | 23.00 29.00 46.50| 46.05             | 28.00 39.00 46.50| −1.63; n.s.                               |
| STAI – trait                   | 37.82           | 30.50 35.00 43.00| 45.54             | 33.00 40.00 46.50| −1.36; n.s.                               |
| GQL – Global health status     | 44.43           | 66.67 75.00 83.33| 42.30             | 58.33 75.00 83.33| −0.381; n.s.                              |
| NV – Nausea and vomiting       | 39.80           | 0.00 0.00 0.00  | 44.57             | 0.00 0.00 8.34   | −1.74; n.s.                               |
| P – Pain                       | 37.32           | 0.00 16.67 33.33| 45.79             | 16.67 33.33 33.33| −1.531; n.s.                              |
| D – Dyspnoea                   | 42.52           | 0.00 0.00 0.00  | 43.24             | 0.00 0.00 0.00   | −0.174; n.s.                              |
| S – Insomnia                   | 39.30           | 0.00 33.33 33.33| 44.82             | 0.00 33.33 66.67 | −1.035; n.s.                              |
| A – Appetite loss              | 41.20           | 0.00 25.00 43.89| 40.00             | 0.00 33.33 33.33| −0.594; n.s.                              |
| C – Constipation               | 38.61           | 0.00 0.00 0.00  | 45.16             | 0.00 0.00 33.33  | −1.616; n.s.                              |
| DIA – Diarrhoea                | 43.77           | 33.33 33.33 33.33| 42.62             | 0.00 33.33 33.33| −0.217; n.s.                               |
| FIN – Financial difficulties   | 46.71           | 0.00 0.00 0.00  | 41.18             | 0.00 0.00 0.00  | −1.669; n.s.                              |
| PF1 – Physical functioning     | 54.73           | 81.67 100.00 100.00| 37.24             | 73.33 86.67 93.33| −3.134; p = 0.002                      |
| RF1 – Role functioning         | 40.66           | 66.67 83.33 100.00| 44.15             | 66.67 100.00 100.00| −0.672; n.s.                              |
| CFI – Cognitive functioning    | 39.95           | 66.67 83.33 100.00| 44.50             | 66.67 83.33 100.00| −0.841; n.s.                              |
| EFI – Emotional functioning    | 48.96           | 75.00 83.33 100.00| 40.07             | 66.67 75.00 95.84| −1.586; n.s.                              |
| SF1 – Social functioning       | 42.75           | 83.33 100.00 100.00| 43.12             | 83.33 100.00 100.00| −0.076; n.s.                              |
### Supplementary Table S3. Cont.

| Item                                                                 | Component |
|----------------------------------------------------------------------|-----------|
| Does your disease make you:                                          |           |
| 42. go on walks less often?                                          | 0.701     |
| 47. go on holidays less often?                                       | 0.649     |
| 43. feel anxious during a walk?                                      | 0.631     |
| 51. feel anxious while on holidays?                                 | 0.629     |
| 20. visit your family less often?                                   | 0.548     |
| 50. adjust the way you spend your holidays?                          | 0.469     |
| 41. feel uncomfortable outside home environment?                     | 0.384     |
| 24. think that your family members feel they are limited by your disease? | 0.370 0.322 |
| 30. close doors and windows more often?                              | 0.782     |
| 31. feel limited while working in the garden?                        | 0.651     |
| 29. install an anti-insect net in windows or doors?                  | 0.600     |
| 32. work in the garden less often?                                   | 0.585     |
| 38. close bottles, cover cups with drinks?                           | 0.548 0.347 |
| 34. eat outside less often?                                          | 0.543 0.431 |
| 52. more careful on holidays?                                        | 0.330 0.452 0.301 |
| 18. use more insect repellents?                                      | 0.451 0.420 |
| 53. use preventive measures on holidays?                            | 0.327 0.423 0.365 |
| 1. work less outside/in open air?                                    | 0.900     |
| 2. work more indoors?                                                | 0.755     |
| 4. feel less comfortable at your workplace?                          | 0.475 0.444 |
| 13. uncomfortable when walking barefoot?                             | 0.347     |
| Angioedema                                                           | 0.758 0.363 |
| 22. talk to other people about your disease?                         | 0.730     |
| 12. wear shoes that cover your feet?                                 | 0.479 0.336 |
| 28. reduce your house chores?                                        | 0.455 0.420 |
| 11. walk barefoot less often?                                        | 0.406 0.410 −0.300 |
| Impaired facial sensation                                             | 0.314 0.345 0.334 |
| Fever                                                                | 0.739     |
| 69. feel anxious more often at daytime than in the evening?          | 0.328 −0.441 0.321 |
| 64. focused on your disease?                                         | 0.323 −0.362 |
| 19. limit the scope of activities performed together with your family or friends? | 0.301 |
| Reflux                                                               | 0.840     |
| Sadness                                                              | 0.705     |
| Effect on friends and family                                         | 0.622     |
| 9. start wearing more fitting or tighter clothes?                    | 0.849     |
| 55. afraid that the medical care abroad is insufficient?              | 0.897     |
| 25. experience discomfort while doing house chores?                  | 0.625     |
| 26. grow fewer flowers at home?                                      | 0.567     |
| 39. limit the number of things to do?                                | 0.344 0.449 |
### Supplementary Table S3. Model matrix Cont.

| Item                                                                            | Component |
|--------------------------------------------------------------------------------|-----------|
| Does your disease make you:                                                     | 1 2 3 4   |
| 40. uncomfortable while doing certain chores?                                   |
| 36. uncomfortable during meals?                                                 | 0.331     |
| 68. limit a spontaneous performance of certain activities?                     | 0.420     |
| 54. carry the contact information of your physician during your holidays?      | 0.842     |
| 14. use a different washing detergent?                                         | 0.860     |
| 17. experience discomfort when using perfume?                                  | 0.522     |

The method of identifying factors – the principal components. Rotation method – Oblimin with Kaiser normalisation.

### Supplementary Table S4. Component matrix

| Item                                                                            | Component |
|--------------------------------------------------------------------------------|-----------|
| Does your disease make you:                                                     | 1 2 3 4   |
| 43. feel anxious during a walk?                                                 | 0.823     |
| 42. go on walks less often?                                                     | 0.804     |
| 20. visit your family less often?                                               | 0.800     |
| 51. feel anxious while on holidays?                                             | 0.743     |
| 47. go on holidays less often?                                                   | 0.732     |
| 53. use preventive measures on holidays?                                        | 0.632     |
| 32. work in the garden less often?                                              | 0.613     |
| 52. more careful on holidays?                                                   | 0.602     |
| 50. adjust the way you spend your holidays?                                     | 0.552     |
| 30. close doors and windows more often?                                         | 0.164     |
| 18. use more insect repellents?                                                 | −0.149    |
| 29. install an anti-insect net in windows or doors?                             | −0.032    |

| Item                                                                            | Component |
|--------------------------------------------------------------------------------|-----------|
| Does your disease make you:                                                     | 1 2 3 4   |
| 38. close bottles, cover cups with drinks?                                      | 0.319     |
| 34. eat outside less often?                                                     | −0.005    |
| 31. feel limited while working in the garden?                                   | 0.503     |
| 1. work less outside / in open air?                                             | 0.086     |
| 2. work more indoors?                                                           | 0.177     |
| 4. feel less comfortable at your workplace?                                     | −0.086    |
| 39. limit the number of things to do?                                           | 0.224     |
| 25. experience discomfort while doing house chores?                             | 0.221     |
| 26. grow fewer flowers at home?                                                 | −0.036    |
| 36. uncomfortable during meals?                                                 | 0.187     |
| 40. uncomfortable while doing certain chores?                                   | 0.424     |
| 68. limit a spontaneous performance of certain activities?                     | 0.320     |
Table 5. QLMS main score in UCK patients (n = 85)

| Score | Frequency | Rate (%) |
|-------|-----------|----------|
| 0     | 16        | 18.82    |
| 1     | 2         | 2.35     |
| 2     | 3         | 3.53     |
| 3     | 3         | 3.53     |
| 4     | 1         | 1.18     |
| 5     | 4         | 4.71     |
| 6     | 6         | 7.06     |
| 7     | 2         | 2.35     |
| 8     | 1         | 1.18     |
| 9     | 2         | 2.35     |
| 11    | 3         | 3.53     |
| 12    | 2         | 2.35     |
| 13    | 4         | 4.71     |
| 14    | 3         | 3.53     |
| 15    | 4         | 4.71     |
| 16    | 2         | 2.35     |
| 17    | 2         | 2.35     |
| 18    | 2         | 2.35     |

Supplementary Table S5. Differences between systemic and cutaneous mastocytosis in QLMS results

| Variable                        | Systemic mastocytosis | Cutaneous mastocytosis | U-Mann Whitney test of group differences |
|---------------------------------|------------------------|-------------------------|------------------------------------------|
|                                 | Mean rank | Quartiles | Mean rank | Quartiles |                                |                          |
|                                 | 25th | 50th | 75th | 25th | 50th | 75th |                                |                          |
| Leisure time                    | 41.06 | 0.00 | 0.00 | 0.71 | 49.74 | 0.00 | 0.33 | 1.00 | -1.428; n.s.                  |
| Protective behaviours           | 42.63 | 0.00 | 0.22 | 0.81 | 44.80 | 0.00 | 0.44 | 0.78 | -0.267; n.s.                  |
| Professional life               | 43.88 | 0.00 | 0.00 | 0.67 | 39.95 | 0.00 | 0.00 | 0.67 | -0.741; n.s.                  |
| Life limitations                | 42.39 | 0.00 | 0.58 | 1.21 | 45.13 | 0.33 | 0.67 | 1.17 | -0.434; n.s.                  |
| Global quality of life in mastocytosis | 42.01 | 0.08 | 0.42 | 0.89 | 46.45 | 0.25 | 0.50 | 0.88 | -0.694; n.s.                  |
Quality of Life in Mastocytosis Scale (QLMS)
Kwestionariusz badający jakość życia u osób chorujących na mastocytozę
N. Spolak-Bobryk, M. Niedoszytko, E. Jassem, M. Chełmińska, M. Lange, M. Majkowicz, B. Niedoszytko, J. Borchet

Imię i nazwisko pacjentki/pacjenta: ...................................................................................................................
Wiek: .................
Płeć:   K     M

Szanowni Państwo,
poniższa tabela przedstawia pytania dotyczące wpływu mastocytozy na Pani (Pana) jakość życia.
Proszę o zaznaczenie, czy i jeśli tak, to w jakim stopniu choroba jest dla Pani (Pana) kłopotliwa.
Proszę pamiętać, że nie ma tu ani dobrych, ani złych odpowiedzi – zależy mi na Pani (Pana) szczerych odczuciach.

Czy Twoja choroba powoduje, że...

| Czy Twoja choroba powoduje, że... | NIE | TAK |
|-----------------------------------|-----|-----|
| 1. Rzadziej spacerujesz?           |     |     |
| 2. Rzadziej wyjeżdżasz na wakacje? |     |     |
| 3. Czujesz się niespokojny w czasie spaceru? |     |     |
| 4. Odczuwasz niepokój podczas urlopu? |     |     |
| 5. Rzadziej odwiedzasz swoją rodzinę? |     |     |
| 6. Dostosowujesz sposób spędzania urlopu? |     |     |
| 7. Częściej zamykasz drzwi i okna? |     |     |
| 8. Odczuwasz ograniczenie podczas pracy w ogrodzie? |     |     |
| 9. Zainstalowałeś (zainstalowałaś) w oknach lub drzwiach siatkę ochronną przed owadami? |     |     |
| 10. Rzadziej pracujesz w ogrodzie? |     |     |
| 11. Zamykasz butelki, przykrywasz naczynia z napojami? |     |     |
| 12. Rzadziej jadasz na zewnątrz? |     |     |
| 13. Jesteś bardziej ostrożna (ostrożny) w trakcie urlopu? |     |     |
| 14. Stosujesz więcej środków odstraszających owady (repelenty)? |     |     |
| 15. Stosujesz jakieś środki ostrożności w trakcie urlopu? |     |     |
| 16. Jesteś zmuszona (zmuszony) pracować mniej na zewnątrz/na wolnym powietrzu? |     |     |

Jak kłopotliwe jest to dla Ciebie?

| Jak kłopotliwe jest to dla Ciebie? | Wcale | Nieznacznie | Dość kłopotliwe | Bardzo kłopotliwe | Uniemożliwia normalne funkcjonowanie |
|-----------------------------------|------|-------------|----------------|-------------------|---------------------------------|
| 1. Rzadziej spacerujesz?           |      |             |                |                   |                                 |
| 2. Rzadziej wyjeżdżasz na wakacje? |      |             |                |                   |                                 |
| 3. Czujesz się niespokojny w czasie spaceru? |      |             |                |                   |                                 |
| 4. Odczuwasz niepokój podczas urlopu? |      |             |                |                   |                                 |
| 5. Rzadziej odwiedzasz swoją rodzinę? |      |             |                |                   |                                 |
| 6. Dostosowujesz sposób spędzania urlopu? |      |             |                |                   |                                 |
| 7. Częściej zamykasz drzwi i okna? |      |             |                |                   |                                 |
| 8. Odczuwasz ograniczenie podczas pracy w ogrodzie? |      |             |                |                   |                                 |
| 9. Zainstalowałeś (zainstalowałaś) w oknach lub drzwiach siatkę ochronną przed owadami? |      |             |                |                   |                                 |
| 10. Rzadziej pracujesz w ogrodzie? |      |             |                |                   |                                 |
| 11. Zamykasz butelki, przykrywasz naczynia z napojami? |      |             |                |                   |                                 |
| 12. Rzadziej jadasz na zewnątrz? |      |             |                |                   |                                 |
| 13. Jesteś bardziej ostrożna (ostrożny) w trakcie urlopu? |      |             |                |                   |                                 |
| 14. Stosujesz więcej środków odstraszających owady (repelenty)? |      |             |                |                   |                                 |
| 15. Stosujesz jakieś środki ostrożności w trakcie urlopu? |      |             |                |                   |                                 |
| 16. Jesteś zmuszona (zmuszony) pracować mniej na zewnątrz/na wolnym powietrzu? |      |             |                |                   |                                 |
17. Jesteś zmuszona (zmuszony) pracować więcej w zamkniętych pomieszczeniach?

18. Czujesz się mniej komfortowo w pracy?

19. Czujesz pewien dyskomfort w czasie wykonywania czynności domowych?

20. Hodujesz mniej kwiatów w domu?

21. Ograniczyłaś (ograniczyłeś) liczbę spraw do załatwienia?

22. Nie czujesz się swobodnie, wykonując pewne obowiązki?

23. Nie czujesz się swobodnie w czasie posiłków?

24. Rzadziej podejmujesz się spontanicznego wykonania pewnych czynności?

KLUCZ:
Ograniczenia dot. czasu wolnego: 1, 2, 3, 4, 5, 6, 10, 13, 15
Zachowania ochronne: 7, 8, 9, 11, 12, 14
Ograniczenia w życiu zawodowym: 16, 17, 18, 21
Ograniczenia w życiu codziennym: 19, 20, 22, 23, 24