

**Study Number:** **Date:**

**Local Contact Email:**

**International Calciphylaxis Collaborative Network (ICCN)**

**Follow up Data Collection Form**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. Laboratory data:  Enter the most recent lab values and please indicate the units in which the values are provided: | | | | |
| Test name | Value | | | Date (dd/mm/yyyy) |
| Creatinine |  | | |  |
| Calcium (total) |  | | |  |
| Corrected Calcium |  | | |  |
| Phosphate |  | | |  |
| Total protein |  | | |  |
| Albumin |  | | |  |
| Alkaline phosphatase (total) |  | | |  |
| Intact PTH (iPTH) |  | | |  |
| Or Bioactive PTH (Whole PTH) |  | | |  |
| CRP |  | | |  |
| Haemoglobin |  | | |  |
|  | | | | |
| 2. Maximum location of lesions at follow-up date: (check all that apply) | | | | |
| abdomen thighs buttock  penis / vulvar area breasts lower extremities (calves, legs)    feet / toes back arms  hands / fingers other | | | | |
| 3. Size of the wound (cm): | | | | |
|  | | | | |
| 4. Has the wound changed? | | | | |
| improving staying the same  deteriorating | | | | |
| 5. Which of the following medical interventions were used to treat the calciphylaxis?  (check all that apply) | | | | |
| calcium containing phosphate binders stopped  vitamin D therapy stopped or reduced  calcimimetics administered  dialysate calcium concentration reduced  dialysis frequency increased  dialysis modality changed, if yes  describe  warfarin/coumadin stopped  iron therapy stopped  bisphosphonates given, if yes  Name:       dose:  route:       length of administration:  sodium thiosulfate, if yes,  Dose:       length of administration:  hyperbaric oxygen treatment  if yes, prescription  oral antibiotics  intravenous antibiotics maggots  antioxidants other | | | | |
| 6. Which of the following surgical interventions were done? (check all that apply) | | | | |
| parathyroidectomy  if yes, date      (dd/mm/yyyy)  wound debridement in operating room    wound debridement outside of operating room (i.e. clinic, home)  amputation revascularisation / angioplasty  skin graft other | | | | |
| 7. Were any other consultants/teams involved in the management of patient? (check all that apply) | | | | |
| surgical vascular  general plastic  wound care specialist other than plastic surgeon  dermatology infectious disease  rheumatology haematology  pain specialist wound follow-up  (pls use wound assessment tool)  pain scale folllow-up (1-10) | | | | |
| 7. Did the patient develop bacteremia? | |  | | |
|  | | | | |
| 8. Did skin lesions resolve? | |  | | |
| If yes approximate date of full healing | | (dd/mm/yyyy) | | |
|  | | | | |
| 9. If the patient died, what was the primary cause of death? | | | | |
|  | | | | |
| 10. If not the primary cause, was calciphylaxis considered a secondary cause of death? | | |  | |
|  | | | | |
| 11. Did the patient withdraw from dialysis prior to death? | | |  | |
|  | | | | |
| ***Any other comments/information*** | | | | |
|  | | | | |

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| ***END of Follow up Data Collection Form*** | |
| ***Thank you very much for submitting your patient details to EuCalNet.***  ***PLEASE ENSURE THE STUDY NUMBER HAS BEEN ENTERED ON PAGE ONE.*** | |
| Please fax the form to **+49 3576287944** | For any questions please email hrothe@moldiag.de |
| You will receive a reminder for follow up data collection in 4 months time if appropriate. | |