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Patient Survey

Impact of Generalized Pustular Psoriasis from the Perspective of People Living with the Condition: Results of an Online Survey

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FINAL PATIENT SURVEY

BRIEF SURVEY INTRODUCTION

HealthiVibe, a division of Corrona, LLC is conducting a survey of people living with a particular health condition to learn more about their experiences living with the disease, receiving treatment and managing their disease.

Participants who qualify and complete the survey in its entirety will receive fair market value compensation for their time. We anticipate that the survey will take 12-15 minutes to complete.

SCREENING QUESTIONS

1. Do you consent to proceed with this survey?

☐ Yes

☐ No [TERMINATE]

2. Do you certify that you are 18 years or older?

☐ Yes

☐ No [TERMINATE]

3. Which of the following conditions or diseases has a doctor told you that you have? [ALLOW

MULTIPLE RESPONSES]

☐ Diabetes (Type I or Type II)

☐ Hypertension

☐ Heart disease

☐ General Pustular Psoriasis (GPP) [REQUIRED, OTHERWISE TERMINATE]

☐ Arthritis

☐ Obesity

☐ Plaque psoriasis

☐ COPD (Chronic Obstructive Pulmonary Disease)

☐ Asthma

☐ Generalized Anxiety Disorder

☐ Depression

☐ Other

[TERMINATE LANGUAGE]

“Thank you, but you do not qualify to complete this survey.”

QUALIFICATION LANGUAGE

You’ve qualified to proceed to the full survey. Participants who complete the entire survey will receive a \$25 gift card for their time.

[THIS PAGE DOES NOT DISPLAY FOR M3 RESPONDANTS]

COVID-19 INSTRUCTIONS

People’s lives have been impacted in many ways by the COVID-19 pandemic. Yet the focus of this current survey is about people’s experiencing living with General Pustular Psoriasis (GPP) **prior to** the COVID-19 pandemic. As you consider and respond to the survey questions, please answer based on your experiences living with GPP **prior to March 2020**. Thank you for your time and consideration.

CORE SURVEY CONTENT

4. How long did it take for you to receive a diagnosis of GPP? Please select the one best response.

- ☐ I received the GPP diagnosis immediately
- ☐ I received the GPP diagnosis within a few weeks
- ☐ I lived with GPP symptoms for months before being diagnosed
- ☐ I lived with GPP symptoms for years before being diagnosed
- ☐ Other

5. What type of healthcare professional correctly made your diagnosis of GPP? Please select the one best response.

- ☐ Dermatologist
- ☐ Rheumatologist
- ☐ Emergency Room Physician
- ☐ Primary care physician (PCP)
- ☐ Other

6. What type(s) of healthcare professional did you see **before** you received your GPP diagnosis? Please select all that apply.

- ☐ Primary care physician (PCP)
- ☐ Emergency Room physician
- ☐ Dermatologist
- ☐ Other

7. **[IF RESPONDENT SELECTS 'MONTHS' OR 'YEARS' RESPONSE OPTION in Q4, OTHERWISE SKIP QUESTION]** What contributed to you living with GPP symptoms for a longer period of time before diagnosis? Please select all that apply. **[ALLOW MULTIPLE RESPONSES]**

- ☐ Had to see multiple healthcare professionals or specialists
- ☐ Was misdiagnosed at first
- ☐ Symptoms were not taken seriously
- ☐ Too sick to self-advocate
- ☐ Too sick to seek medical treatment
- ☐ Affordability of medical care/lack of health insurance
- ☐ Limited access to healthcare specialists
- ☐ Other

8. Please select the current treatment(s) that you are receiving for GPP. Select all that apply.

[ALLOW MULTIPLE RESPONSES]

- ☐ Acitretin
- ☐ Remicade® (anti-TNF inhibitors, a type of biologic)
- ☐ Stelara® (IL-12/23i inhibitor, a type of biologic)
- ☐ Cosentyx®, Taltz®, Siliq® (IL-17i inhibitors, a type of biologic)
- ☐ Ilumya™, Tremfya®, Skyrizi™ (IL-23i inhibitors, a type of biologic)
- ☐ Cyclosporine
- ☐ Methotrexate
- ☐ Ultraviolet light B (UVB)
- ☐ Oral PUVA (the light-sensitizing drug psoralen plus ultraviolet light A)
- ☐ Oral steroids
- ☐ Retinoids
- ☐ Topical corticosteroids
- ☐ Topical treatment (other)
- ☐ Triamcinolone with wet body wraps
- ☐ Not sure **[IF SELECTED, DESELECT ALL OTHER RESPONSE OPTIONS AND SKIP TO QUESTION 14] [IN QUESTION 10 THIS OPTION WILL APPEAR AND IF SELECTED WILL DESELECT ALL OTHER RESPONSE OPTIONS AND CONTINUE TO QUESTION 11]**

- ☐ Other type of treatment (specify) [ALLOW WRITE-IN]

ALLOW MULTIPLE UP TO 3 TOTAL “Other type of treatment (specify) OPTIONS”

9. When you are experiencing a flare, does your physician **“add on”** any additional medication(s)?

- () Yes
() No
() I don’t know

10. [IF RESPONDENT SELECTS ‘YES’ RESPONSE OPTION in Q9, OTHERWISE SKIP QUESTION] What medications does your physician **add** when you’re in a flare? Please select all that apply. [ALLOW MULTIPLE RESPONSES]

[DISPLAY ALL MEDICATION THAT WERE **NOT** SELECTED FROM LIST FROM Q8 WITH OPTION TO ALLOW MULTIPLE UP TO 3 TOTAL “Other type of treatment (specify)”]

11. When you are in a flare, does your physician instruct you to **discontinue (stop)** any of your current medications?

- () Yes
() No
() I don’t know

12. [IF RESPONDENT SELECTS ‘YES’ RESPONSE OPTION in Q11, OTHERWISE SKIP QUESTION] You indicated that you **discontinue or stop** one or more current medications when you are experiencing a worsening or flare in your GPP. Please select the medications that you **discontinue or stop**. [ALLOW MULTIPLE RESPONSES]

[DISPLAY THE MEDICATIONS RESPONDENT **SELECTED** IN Q8 WITH STATIC OTHER OPTIONS BEING PASSED IN]

13. When you are in a flare, does your physician instruct you to **switch** to a different medication?

- ☐ Yes
- ☐ No
- ☐ I don't know

TOPIC: Flares

14. How do you define a worsening (or “flare”) in your GPP? Please select all that apply.

[RANDOMIZE RESPONSE OPTIONS, EXCEPT WITH ‘Other’ AND ALLOW MULTIPLE RESPONSES]

- ☐ More pustules
- ☐ Plaque begins to spread or cover more area
- ☐ More crust
- ☐ Greater sensitivity to temperature changes
- ☐ Increased pain in hands, arms, feet or toes
- ☐ More pain overall
- ☐ Changes in mood
- ☐ Fatigue
- ☐ Burning sensation
- ☐ Itching
- ☐ Pain
- ☐ Fever
- ☐ Other

15. [PROGRAM TO DISPLAY RESPONSES SELECTED IN Q14] Please rate how burdensome your symptoms are when your GPP is worsening (or you’re in a “flare”). Please use a scale of 0 to 10 where 0=No burden and 10=Extreme burden.

[PROGRAM TO DISPLAY ON A 0-10 SCALE, RESPONDENT TO RATE EACH FLARE SYMPTOM SELECTED IN Q14]

16. **In the past 12 months**, how often have you experienced worsening (or “flares”) in your GPP?

- ☐ Never
- ☐ Once
- ☐ 2-3 times
- ☐ 4-5 times
- ☐ 6 or more times
- ☐ Other


17. What factors or conditions have you attributed to worsening (or “flares”) in your GPP? Please select all that apply. **[RANDOMIZE RESPONSE OPTIONS, EXCEPT WITH ‘Other’ AND ALLOW MULTIPLE RESPONSES]**

- ☐ Starting a new medication
- ☐ Stopping a current medication(s)
- ☐ Change in dose of current medication(s)
- ☐ Too much exposure to UV (ultraviolet) light
- ☐ Pregnancy
- ☐ Systemic steroids (sometimes called glucocorticoids or cortisones, including Prednisone)
- ☐ Hormonal changes
- ☐ Seasonal changes
- ☐ Environmental changes
- ☐ Infections
- ☐ Emotional stress
- ☐ Other


TOPIC: Quality of Life

18. Please indicate how much GPP impacts your life when you're **NOT** experiencing symptoms.

Please use a scale of 0 to 10 where 0=No impact and 10=Extreme impact.

Task/Aspect of Life [FORMAT TO A 0-10 SCALE]	
Ability to complete household chores such as making meals, housecleaning or laundry	
Ability to socialize with family, friends or neighbors	
Ability to attend important life events such as birthdays, graduations, weddings or other celebrations	
Ability to complete errands such as shop for groceries or go to a local store	
Ability to wear shoes	
Ability to exercise or engage in physical activity	
Ability to be intimate with a spouse or partner	

19. Please indicate how much GPP impacts your life when you **are experiencing a worsening (a flare) in your disease** using a scale of 0 to 10 where 0=No impact and 10=Extreme impact.

Task/Aspect of Life [FORMAT TO 0 TO 10 SCALE]	
Ability to complete household chores such as making meals, housecleaning or laundry	
Ability to socialize with family, friends or neighbors	
Ability to attend important life events such as birthdays, graduations, weddings or other celebrations	

Ability to complete errands such as shop for groceries or go to a local store	
Ability to wear shoes	
Ability to exercise or engage in physical activity	
Ability to be intimate with a spouse or partner	

TOPIC: Treatment Pathway

20. When your GPP is in **control**, how often do you see the physician that is treating/managing the disease?

- ☐ Monthly
- ☐ Every 3 months
- ☐ Two times a year
- ☐ Annually
- ☐ Other

21. When your GPP is **worsening or in a flare**, how often do you see the physician that is treating/managing the disease?

- ☐ Weekly
- ☐ Every 2 weeks
- ☐ Monthly
- ☐ Every 3 months
- ☐ Two times a year
- ☐ Annually
- ☐ Other

22. **In the past 12 months**, how often have you been to an Emergency Room due to worsening GPP?

- ☐ 0

- () 1-2 times
- () 3-4 times
- () 5 or more times
- () Not sure

23. **In the past 12 months**, how often have you been admitted to the hospital for an overnight stay or longer due to worsening GPP?

- () 0
- () 1-2 times
- () 3-4 times
- () 5 or more times
- () Not sure

24. Please respond to the following statements about the management of your GPP using a 1 to 5 scale where 1=Strongly disagree and 5=Strongly agree.

[FORMAT 5-POINT SCALE WITH QUALIFIERS]	Strongly Disagree 1	Disagree 2	Neutral/ Not sure 3	Agree 4	Strongly Agree 5
My physician knows how to best treat my GPP					
My physician does not understand the level of physical pain that I experience from GPP					
My physician does not understand the level of emotional or psychological pain that I experience from GPP					

My physician provides me with up-to-date treatment information about GPP					
I understand my GPP diagnosis					
I understand how to manage my GPP to avoid my disease worsening					
I feel comfortable asking questions of my healthcare provider about my GPP					

25. If a new treatment was available for GPP, what would you want to know to help make a decision before starting it? Please select all that apply. **[RANDOMIZE RESPONSE OPTIONS, EXCEPT WITH 'Other' AND ALLOW MULTIPLE RESPONSES]**

- ☐ How the new treatment is administered (e.g., tablet, injection, topical)
- ☐ Does the new treatment require stopping one of my current medications?
- ☐ Will I become sicker or worse before my GPP improves?
- ☐ Clinical trial data from the new treatment
- ☐ How long would I have to wait before I saw benefits from the new treatment
- ☐ Side effects of the new treatment
- ☐ How many other people with GPP experienced improvements in their disease?
- ☐ Other

TOPIC: Patient Management of Disease

26. Do you use any over-the-counter medicines or “home remedies” that provide relief from your GPP symptoms?

☐ Yes

☐ No

27. **[IF RESPONDENT SELECTS ‘YES’ RESPONSE OPTION in Q26, OTHERWISE SKIP QUESTION]** What are some of the over-the counter or “home remedies” that you have found provided relief from GPP symptoms? Please select all that apply. **[RANDOMIZE RESPONSE OPTIONS EXCEPT WITH ‘Other’, AND ALLOW MULTIPLE RESPONSES]**

- ☐ Oatmeal baths
- ☐ Occlusion therapy (wrapping skin in plastic wrap following application of ointment)
- ☐ Allergy medicine
- ☐ Ibuprofen or Tylenol
- ☐ Ointments such as Vaseline or petroleum jelly
- ☐ Taking cool baths
- ☐ Taking warm baths
- ☐ Ice packs
- ☐ Climate or temperature changes
- ☐ Other

28. What kinds of physical or mental activities provide relief from your GPP symptoms? **[ALLOW MULTIPLE RESPONSES]**

- ☐ Meditation or mindfulness
- ☐ Reading
- ☐ Exercise
- ☐ Swimming
- ☐ Yoga or pilates
- ☐ Walking outside

- ☐ Listening or playing music
- ☐ Participating in a favorite hobby
- ☐ Support groups
- ☐ Other

TOPIC: Residual Disease

29. When you are **not** in a flare, how would you describe your GPP symptoms? Please select the one best response.

- ☐ No symptoms
- ☐ Manageable, not too much pain
- ☐ Moderate pain
- ☐ Severe pain, it never goes away
- ☐ Other

30. What does your GPP look like when you are **not** in a flare? Please select all that apply.

[ROTATE RESPONSE OPTIONS EXCEPT WITH 'Other', AND ALLOW MULTIPLE RESPONSES]

- ☐ Crust begins to harden
- ☐ Pustules no longer appear
- ☐ Crust begins to crack and fall off
- ☐ Scarring
- ☐ Changes in skin color
- ☐ Dry, flaky skin
- ☐ Fewer pustules
- ☐ Pustules begin to dry
- ☐ Other

31. What does it mean to you to have your GPP “under control”? Please select all that apply.

[ALLOW MULTIPLE RESPONSES]

- ☐ I have little to no symptoms

- ☐ I have some symptoms, but they do not cause pain or discomfort
- ☐ I have some symptoms with minimal pain
- ☐ I am able to engage in activities that I enjoy
- ☐ Other: please explain [ALLOW WRITE-IN, MAX 250 WORDS]

TOPIC: Disease Severity and Disease Control

32. In your opinion, how **severe is your GPP when it is under control**? Please use a 0 to 10 scale where 0="Not severe" and 10="Extremely severe".

[DISPLAY ON A 0-10 SCALE WITH SCALE QUALIFIERS]



33. In your opinion, how **severe is your GPP when your disease is in a flare**? Please use a 0 to 10 scale where 0="Not severe" and 10="Extremely severe".

[DISPLAY ON A 0-10 SCALE WITH SCALE QUALIFIERS]



34. How well do you think your GPP is being **controlled** by your current prescription medications or treatments? Please use a 0 to 10 scale where 0="Uncontrolled" and 10="Extremely controlled".

[DISPLAY ON A 0-10 SCALE WITH SCALE QUALIFIERS]



TOPIC: Other Patient Feedback about Living with GPP

35. When your disease is **under control (not in a flare)**, how much time would you estimate that your physician spends with you during a visit to discuss your GPP?

- ☐ Less than 10 minutes
- ☐ 10 to 20 minutes
- ☐ 20 to 30 minutes
- ☐ More than 30 minutes

36. When you are **experiencing worsening symptoms or in a flare**, how much time would you estimate that your physician spends with you during a visit to discuss your GPP?

- ☐ Less than 10 minutes
- ☐ 10 to 20 minutes
- ☐ 20 to 30 minutes
- ☐ More than 30 minutes

37. What do you wish you had time during an office visit to discuss with your physician about living with GPP? Please select all that apply. **[ALLOW MULTIPLE RESPONSES]**

- ☐ New treatment options for GPP
- ☐ Clinical trials that I might be eligible for screening or participation
- ☐ Impact of the disease on my personal life
- ☐ Impact of the disease on intimate or sexual relationship(s)
- ☐ Other

38. What else should doctors understand about patients' experiences living with GPP? Please select all that apply. **[ALLOW MULTIPLE RESPONSES]**

- ☐ Living with constant fear of their disease worsening/next flare
- ☐ Fears about their disease worsening with age
- ☐ Feelings of hopelessness and depression that sometimes accompanies the disease
- ☐ Feelings of anxiety about the disease
- ☐ Worry that current medication(s) will stop working
- ☐ Other

DEMOGRAPHIC QUESTIONS

A few final questions...

39. What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other

40. What range best reflects your age?

- ☐ 18 to 29 years
- ☐ 30 to 39 years
- ☐ 40 to 49 years
- ☐ 50 to 59 years
- ☐ 60 to 69 years
- ☐ 70 years or older

41. Prior to the COVID-19 epidemic, were you?

- ☐ Working (full or part time)
- ☐ A student (full or part time)

- ☐ Homemaker
- ☐ Retired
- ☐ Disabled
- ☐ Not currently working
- ☐ Other

42. How long ago were you diagnosed with GPP?

- ☐ Within the past year
- ☐ 1-3 years
- ☐ 4-6 years
- ☐ 7-10 years
- ☐ More than 10 years
- ☐ Prefer not to answer

43. What is the geographic area in which you live?

- ☐ Northeast (New England, Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, New Jersey, New York, and Pennsylvania)
- ☐ Midwest (Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, and South Dakota)
- ☐ South (Delaware, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, District of Columbia, West Virginia, Alabama, Kentucky, Mississippi, Tennessee, Arkansas, Louisiana, Oklahoma, and Texas)
- ☐ West (Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, and Wyoming, Alaska, California, Hawaii, Oregon, and Washington)

Thank you for your time and willingness to complete this survey.

[SURVEY END]
