

## REPORT OF GORLIN UNCOVERED.

### SUMMARY

An on-line survey ran from 29/7/18 to 4/7/18. Participants could volunteer if they were 18 or over and had Gorlin syndrome. We asked participants to respond for themselves. There were 39 responses, including one form an individual who said she was not diagnosed with Gorlin and had no BCCs in the past year. She has been excluded. Of the remaining 38, 23 were women.

There were insufficient numbers to do multivariate analyses or significance tests.

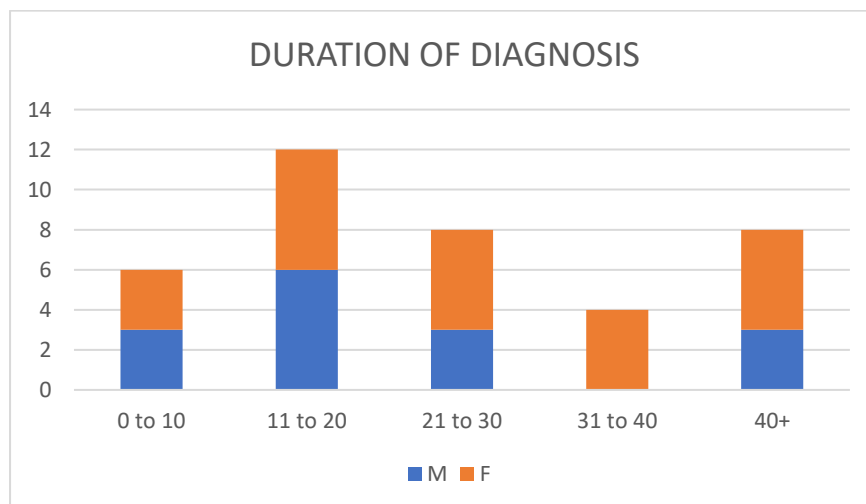
The use of Factor 50 sunscreen on the face, neck, ears, chest and arms, along with a hat, on sunny days was the most frequent current UV avoidance strategy. The use of more intense (daily use) or less intense strategies was not correlated with gender, duration of diagnosis or number of BCCs.

Psychological and social problems caused by GS were frequent, as previously reported. Externally located problems with work and relationships were associated with the number of BCCs in the previous year.

Adherence to a new drug regime was anticipated to be high for most people, particularly in individuals with long histories and those that had more assiduous UV avoidance strategies. The main hope for a new drug was to reduce the need for future BCCs and their painful and uncomfortable treatment.

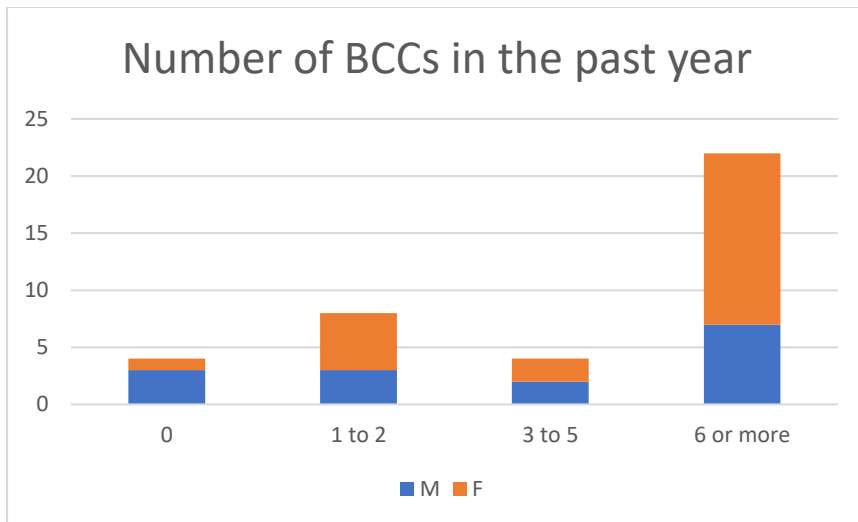
### DURATION

The median duration of diagnosis was 21 to 30 years.



### BCCs PER YEAR

The median number of BCCs in the past year was more than 6. Women reported proportionately more BCCs in the past year.

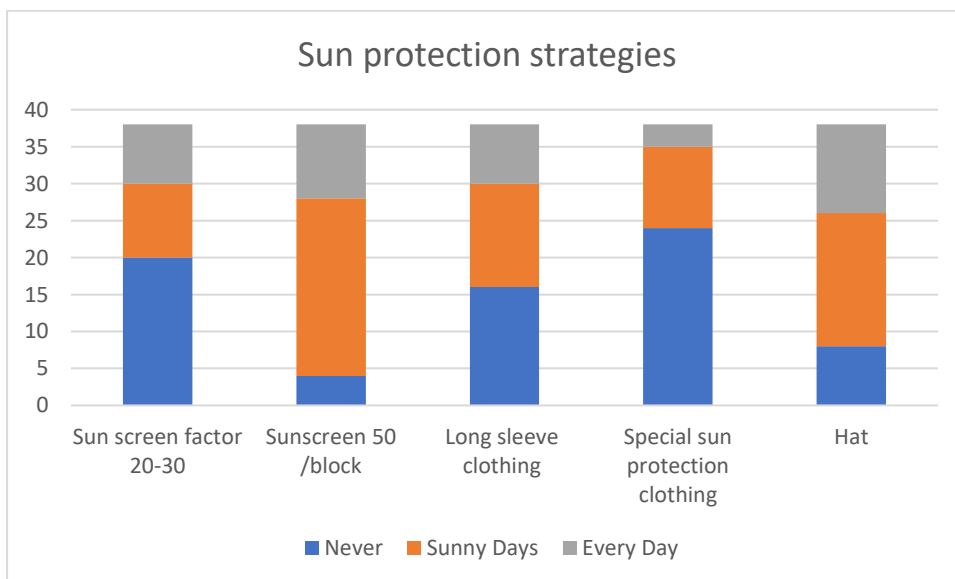


There was a modest tendency for people with longer durations to have had more BCCs in the past year:

		BCCs in the past year	
		5 or less	6 or more
Duration of diagnosis	0 to 20	9	9
	21+	7	13

### SUN PROTECTION STRATEGIES

Using Factor 50 sun screen and a hat on sunny days were the most popular sun protection strategies:



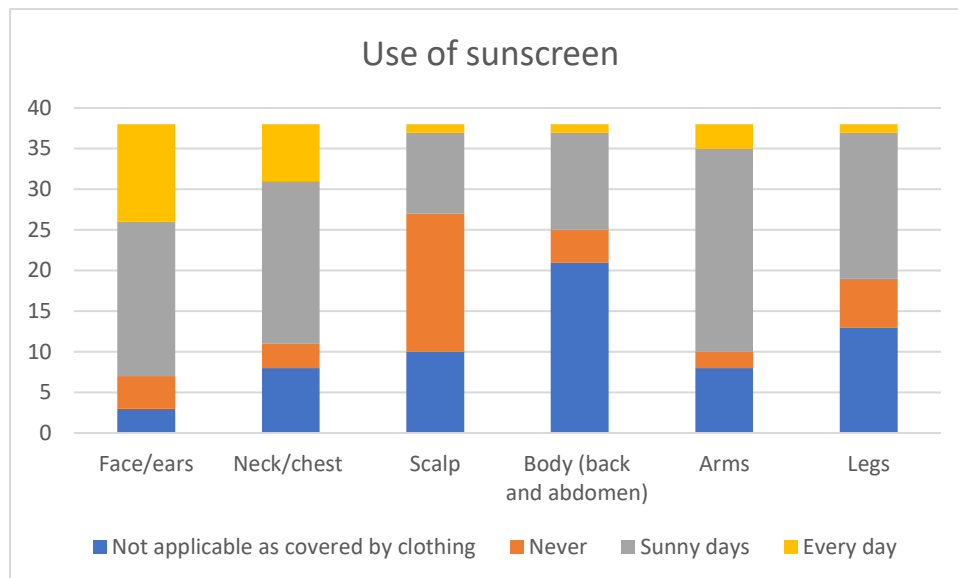
Only one respondent said they didn't use any protection. 4 people said they use both a hat and Factor 50 sunscreen every day and 13 people said they use both Factor 50 sunscreen and a hat on sunny days only.

Respondents were classified as 1) infrequent protectors if they only had one or no strategies for protection (2 people), 2) sunny day protectors if they used two or more strategies for sunny days or every day (25 people) and 3) every day protectors if they used two or more strategies every day (11 people).

There were no clear relationships between strategy and gender, numbers of BCCs or duration.

### SUN SCREEN USE

Sun screen was most frequently applied to the face, ears, neck, chest and arms.

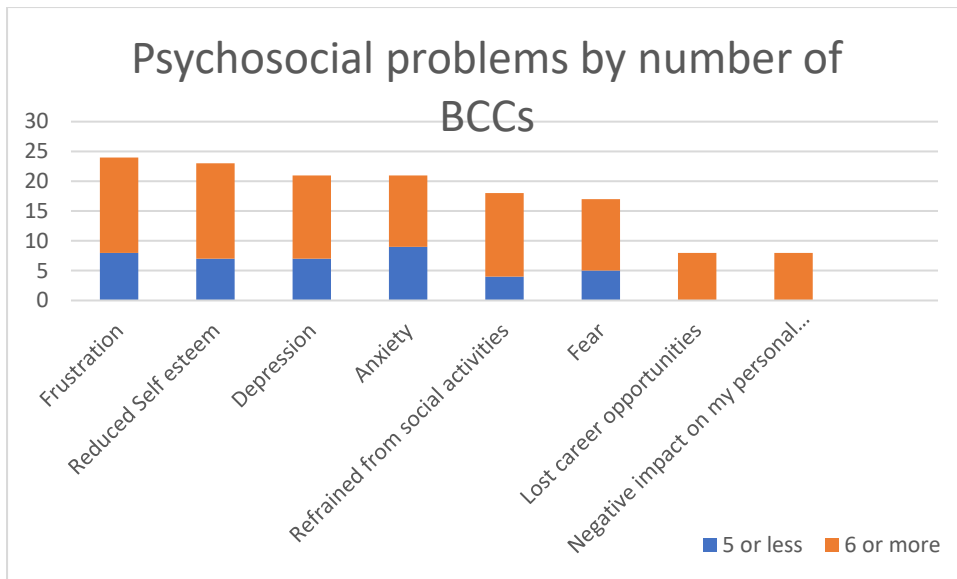


Respondents were classified as 1) low sunscreen users if they only applied to one or no sun exposed areas (1 person), 2) sunny day sunscreen users if they applied to two or more sun exposed areas on sunny days or every day (15 people) and 3) every day, extensive sunscreen users if they applied to two or more exposed areas every day (22 people).

There was only very modest correlations between general sun protection strategies, gender, number of BCCs and duration and the use of sunscreen.

### PSYCHOSOCIAL PROBLEMS

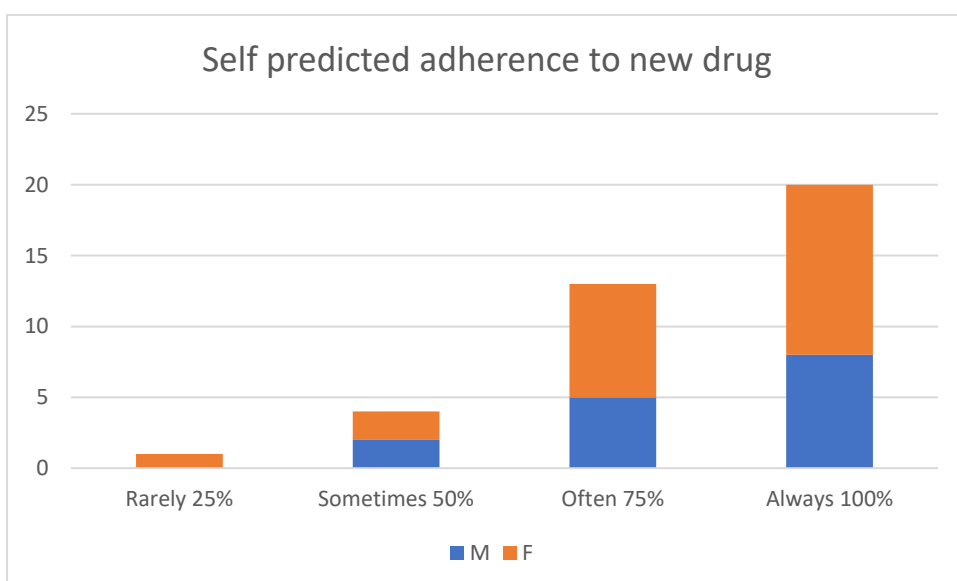
Participants were asked if they had ever been affected by various problems. Numbers of BCCs in the previous year had the biggest impact on these – especially social factors for example work and relationships. Gender and disease duration had less clear impact. There was no clear relationship between psychosocial factors and current UV avoidance strategy.

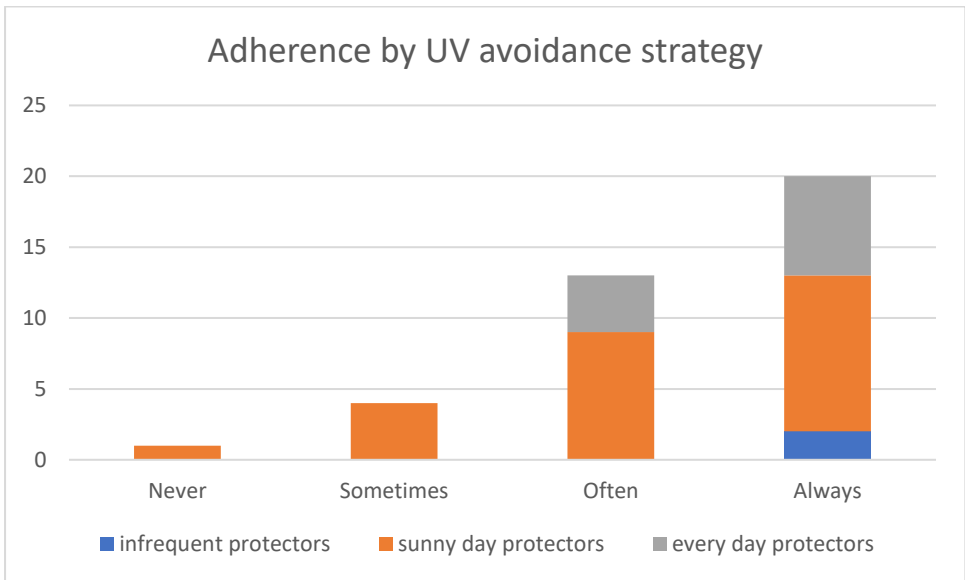
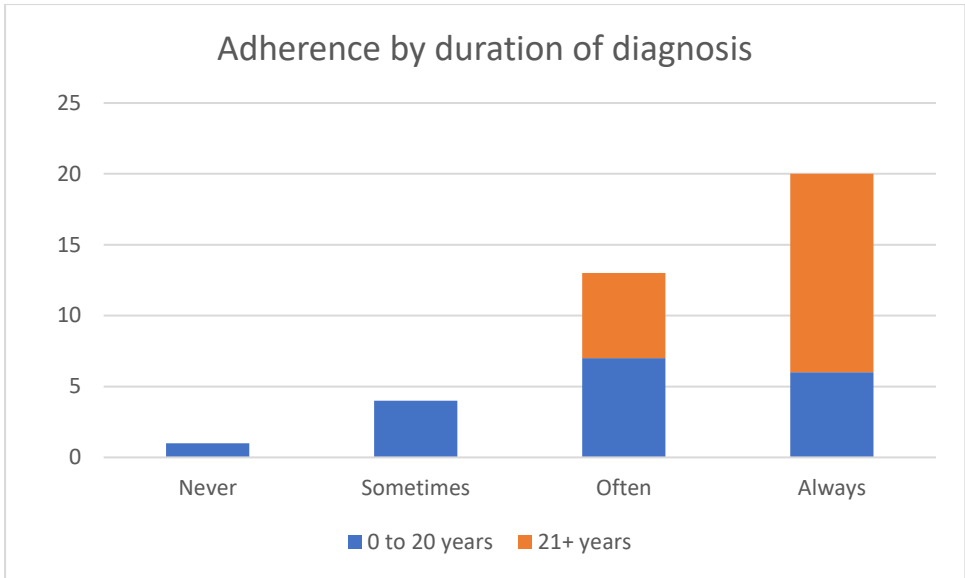


'Guilt' and 'low feeling' about affected children were mentioned in free text, along with one problem with jaw cysts. One woman, only mildly affected herself, said a concern for her was that 'I have very few photos with my children'.

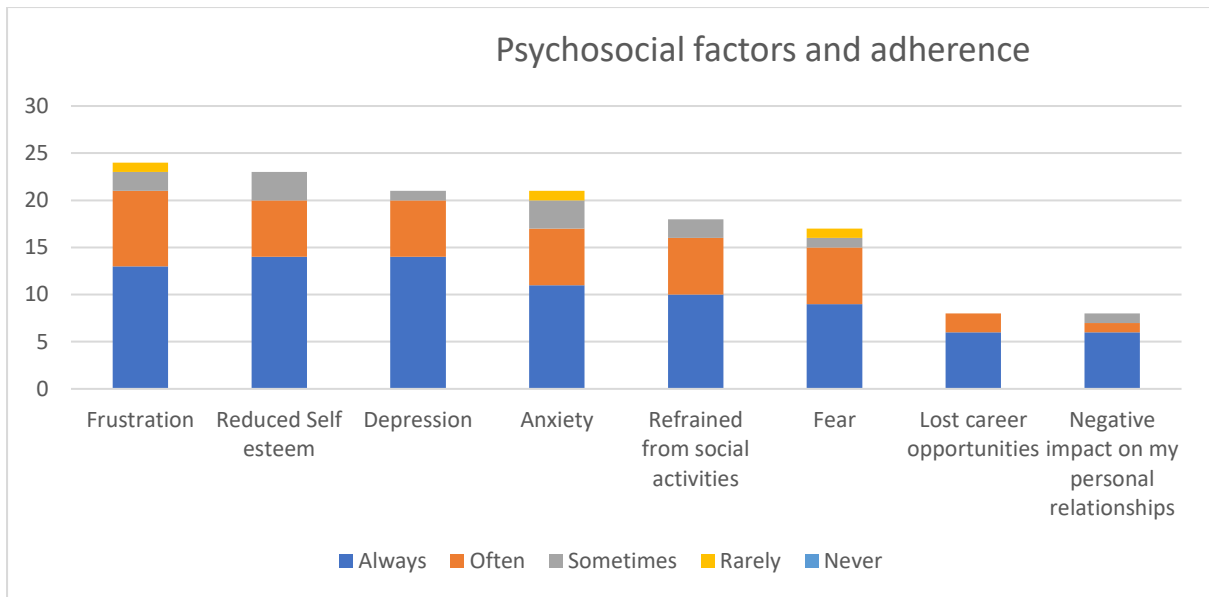
#### ADHERENCE TO NEW DRUG.

Participants were asked how often they thought they may use a new drug applied to the skin. Adherence did not appear to be related to gender, but did appear to correlate with both duration of diagnosis and UV avoidance strategy – adherence was greater in people with long durations and who practiced daily avoidance strategies. There were no clear relationships between number of BCCs in the previous year or sunscreen use and adherence





There was no clear relationship between reported psychosocial factors and adherence. The data do not support the idea that fear, frustration or anxiety would drive higher adherence.



### HOPES FOR A FUTURE TREATMENT

Participants were asked to select one of four possible hopes for a new treatment:

