



INSIDE PEOPLE



SONJA WILLEMSSEN
AGE 23, NIJVERDAL
**WHEN DO YOU REALLY GET
REMINDERS THAT YOU DON'T GO
OUTSIDE MUCH?**

| Well, my skin doesn't tan. At all.
So people constantly ask me if
I'm sick. The one time I'd really
like to have a little color is when
I get married. Otherwise, I'll look just
like my bridal gown.

FERRY HASSELMAN
AGE 32, AMSTERDAM
**WOULD YOU LIKE TO
WORK OUTSIDE?**

| Yeah, as a motorcycle cop.
Then I could ride for a living.
The uniform and all the gear
would protect me from the sun.
Except when I was talking to people
I'd have to open up the helmet,
which would expose me to the sun.
So I wouldn't be able to do that job.

ERWIN OKKEN
AGE 17, HOLLANDSCHEVELD
**WHAT DO YOU MISS MOST ABOUT
NOT BEING OUTSIDE MUCH?**

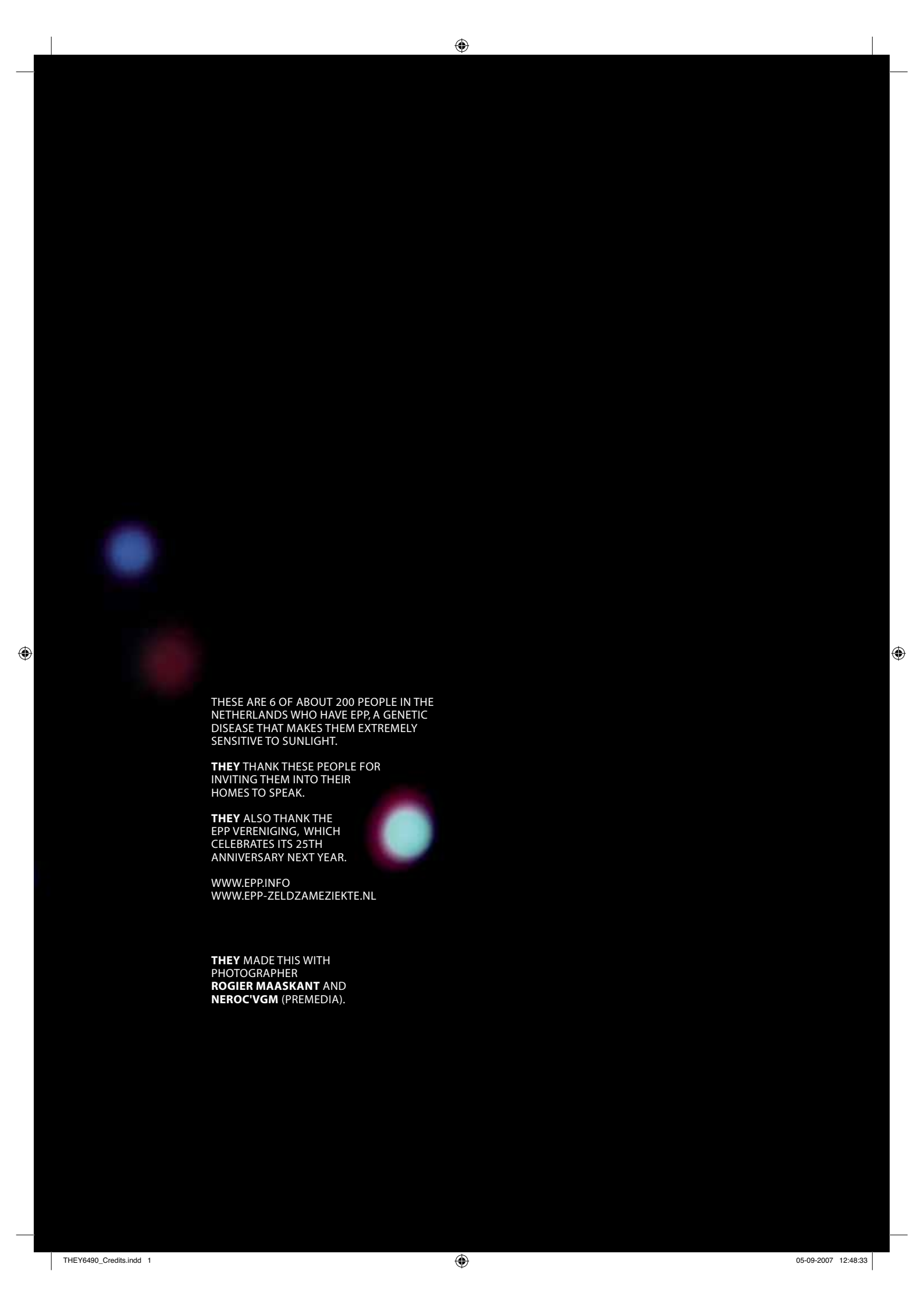
| Going out with my friends.
They invite me a lot to go
play sports and stuff.
But of course they usually want to
go in the afternoon just because
that's when people normally go out
to play. And I'm not the kind of guy to
be like "C'mon can't everybody just
wait till tonight so I can come too?"

GERARD HEERSPINK AND
ADDY JANSSEN HEERSPINK
AGES 63 AND 50, AXEL
**AS BROTHER AND SISTER, DO YOU
SHARE ANY COMMON MEMORIES ABOUT
GROWING UP WITH YOUR CONDITION?**

| When we stayed in the sun too long
our skin would turn red and swell up
as though we had been lying in
nettles. We looked just like little
Michelin Men. Our eyes would get
so swollen we had to pry them open.
To cool off we'd go down to the
basement together, and just
sit there for hours.

SUZANNE TALENS
AGE 17, BEILEN
**FOR WHAT WOULD YOU
BRAVE THE OUTSIDE?**

| A Red Hot Chili Peppers concert!
I went to the show in Goffert Park
this summer, even though it meant I
might be sick for five days afterwards.
I was all wrapped up with a hood,
jacket, scarf, gloves and an umbrella.
I got there at 11 in the morning—
nine hours early—just so I could get
close to the stage.



THESE ARE 6 OF ABOUT 200 PEOPLE IN THE NETHERLANDS WHO HAVE EPP, A GENETIC DISEASE THAT MAKES THEM EXTREMELY SENSITIVE TO SUNLIGHT.

THEY THANK THESE PEOPLE FOR INVITING THEM INTO THEIR HOMES TO SPEAK.

THEY ALSO THANK THE EPP VERENIGING, WHICH CELEBRATES ITS 25TH ANNIVERSARY NEXT YEAR.

WWW.EPP.INFO
WWW.EPP-ZELDZAMEZIEKTE.NL

THEY MADE THIS WITH PHOTOGRAPHER **ROGIER MAASKANT** AND **NEROC'VGM** (PREMEDIA).