List Cure for EB Warning:

Dear All
I have just been informed that Dr Kozak in Romania is again advertising a "Cure for EB" and other skin diseases

- Medicina alternativa/Alternative Medicine
  Medicina naturista - metoda Kozak
  http://kozak.kappa.ro/
  Medicina naturista - metoda Kozak - o speranta in bolile de piele
  Kozak Methods
  Kozak Methods - a hope in the skin diseases

He has been very well known over the years and in the past an enormous amount of money (50,000 Euro per child) has been raised by EB families to send their children to him to be cured. I understand that his methods are based on sunshine and a good healthy diet.

We believe he has now retired and his son has taken over the 'business'

This is a friendly warning to you all not to be tempted to send anyone to his clinic

With best wishes
Janice Carrera
Debra International Support

This link doesn't work. I have Googled all the relevant words and nothing came up. Maybe someone from DebRA Romania can supply more information. If whoever is behind this "cure" is a charlatan, then obviously it is really important that vulnerable EB families are not taken in. For anyone who is unaware of the history behind this, I have summarised below the information that I have.

Over 20 years ago, my predecessor Sue Allman RD and Paediatric Dermatologist Dr David Atherton visited Pavel Kozak's "institute" in the the foothills of the Pyrenees. This was written up in a report for DebRA UK entitled "The Pavel Kozak Institute- reflections of a visiting paediatric dermatologist". David noted Kozak's unwillingness to describe his methods in any detail and his apparent sense of hostility from mainstream medical practitioners. However, he noted the "family" and "holiday" atmospheres and the fact that Kozak and his wife were like "kindly but firm parents" to the often single parents who had taken their EB children there. He suggested that things could be learned from Kozak's approach, not least the nature of the care environment and a holistic approach.

Kozak's claim to cure EB by an exclusion diet combined with topical and systemic treatments was disproved in an open evaluation of the regimen (Haber RM, Ramsay CA, Boxall LBH. Epidermolysis bullosa. Assessment of a treatment regimen. Int J Dermatol, 1985, 24 324-8). Sue Allman found the diet very worrying in terms of nutritional adequacy and indeed a letter from Haber et al describing their study states "To protect the patients from harm the diet was amended to ensure adequate intake according to age" (Haber RM, Ramsay CA, Boxall LBH. Assessment of a treatment for epidermolysis bullosa. Letters, Can Med Assoc J. Vol 131, 1984).


Mr Kozak's regime for epidermolysis bullosa. Correspondence, J Amer Acad Derm, Vol 8, No4, 1983.

It would be nice to think that Kozak's son would be more open to scrutiny than his father.

Kind regards, Lesley Haynes RD
Dear Lesley
Thanks so much for the information - this is why we must all communicate with each other internationally! We cannot have our EB families exploited in this way.
Best wishes Janice

I had the same problem as you did, Lesley, the link did not open for me. More information about Kozak's protocol is found here http://www.cmaj.ca/cgi/content/abstract/130/6/715?ck=nck, and a commentary about the Kozak protocol by Dr. Colin Ramsay is attached (midway through the first page of the attached, continues onto the second page).
Here is the tale of one of Kozak's patients:  http://ebinfo.homestead.com/ebandme.html
Best regards,
Gena

Dear Janice and Lesley, (and all),
This I found about Pavel Kozak.
http://www.kozak-dermato.ro/
http://www.dermatology-kozak.com/tratamente-boli-de-piele.php
Curious if they still are working? and how..
I just sent in a form (see below) (just to see if and who will answer back).
I know Pavel Kozak from when i was a teenager. (that was about 27 yrs ago)
So I was surprised at least to read this mail about him.
That's why I reply...
Diagnoses
Send us informations about you and your desease and we will try to help you to find the best remedy.

Name and surname:  
E-mail: 
Age:  
Weight: (Kg):  
Height: (cm):  
Address: 
Phone:  
Your message to us: 

*(describe your symptoms)*

What other diseases you have/medicines you take:
Well.. if I hear more things about the Kozak's ..I also let you know.
Greetings,
Yvonne Sellies

Thanks a lot Yvonne
Please let us know if you receive a reply we will be most interested, did you personally have treatment from Dr Kozak and if so what was the result?
Best wishes
Janice