

Anderson, Julia

From: Christopher Ludlam [Christopher.Ludlam@GRO-C]
Sent: 09 March 2002 13:25
To: Liz Chalmers; Anderson, Julia; Campbell Tait; 'Gordon Lowe'; Henry Watson; Bill Murray; Philip Cachia; Isobel Walker; Angela Thomas; Lishel Horn
Subject: Fw: Letter to haemophilia patients

Herewith the response from the Incidents Panel and my initial reply. I sent to the Panel a copy of the letter we proposed to sent to patients who received concentrate 1987-89 along with the letter etc we sent last year. I should be grateful for your views on the Panel's response and how we should proceed. There is a CFWP meeting on 25th March - potentially we could have a short Haem Directors premeeting to discuss this. Look forward to hearing from you
C

Christopher A. Ludlam
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----- Original Message -----

From: "Christopher Ludlam" <Christopher.Ludlam@GRO-C>
To: <Philippa.Edwards@GRO-C>
Cc: "Aileen Keel" <Aileen.Keel@GRO-C>
Sent: Saturday, March 09, 2002 1:18 PM
Subject: Re: Letter to haemophilia patients

e-mail reply from
Prof Banner.

> Thank you. One of our concerns is to be as open as possible with out
> patients and we are concerned that further delay might be construed as
with
> holding information. It would be very helpful to know when the Incidents
> Panel could come to a view. Apart from further information being requested
> from the manufacturer what additional information will be the Panel
require.
> If Haemophilia Directors are not considered sufficiently knowledgeable on
> this topic could you tell me who would provide the counselling to our
> patients or what training would be given Haemophilia Directors so that
there
> are appropriately informed.
> I am sending your response to my colleagues so that we can together reach
he
> most appropriate way forward.
> With regards
> Christopher Ludlam
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> Christopher A. Ludlam
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----- Original Message -----
From: <Philippa.Edwards@ GRO-C>
> To: <Christopher.Ludlam@ GRO-C>
> Cc: <Aileen.Keel@ GRO-C> <l.southgate@ GRO-C>
> <J.Oneill@ GRO-C> <patricia.hewitt@ GRO-C>
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> "Michael Banner" <Michael.Banner@ GRO-C> "Michael Banner"
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> <Charles.Lister@ GRO-C> <glenda.mock@ GRO-C>
> <martin.donaghy@ GRO-C> <mike.simmons@ GRO-C>
> <Pat.Troop@ GRO-C>
> Sent: Friday, March 08, 2002 3:14 PM
> Subject: Re: Letter to haemophilia patients

>>>>>
RESTRICTED MEDICAL

>> Dear Dr Ludlam
>> Thank you for sending your draft letter to the Panel for comment.
>> Having discussed the matter with Panel Members, I would like to draw
your
>> attention to the concerns we have about the letter.
>>
>> 1. Haemophiliac patients represent a special group and the Panel
>> acknowledges that providing adequate support to clinicians providing
>> information to patients may be less of a problem than in other
>> circumstances. However, there remained some concern that not all
>> recipients of the letters would be in frequent contact with their
>> consultants and therefore might not receive the necessary counselling.
>> Furthermore, the Panel was concerned that not all haemophilia centres
>> would
>> be well informed about CJD and in particular, the uncertainties
>> surrounding
>> the potential for transmission through products derived from blood.
>>
>> 2. The Panel also expressed some concern about the lack of details
>> available for this incident, which precludes a better assessment of the
>> potential risks. It appears that the patients will be given the option
of
>> finding out whether they have received any of the involved batches, but
>> will not be able to learn anything more in relation to their potential
>> exposure. There may be a proportion who the Panel would classify as
>> contactable, who should be alerted to their potential exposure in order
to
>> safeguard public health. The option not to be told may therefore
>> subsequently be overruled at a later date on public health grounds. The
>> exposure of other patients may be unlikely to be significantly above
>> background. Although the risks are not known with any certainty, the
>> Panel's analysis does allow an estimate of the potential exposure. The
>> Panel has also been contacted by the Dr Anderson from the Haemophilia
>> Centre in NI and been provided with details of doses of specific batches
>> received by unidentified individual patients. Details of the products
and
>> pool sizes have been requested from the producers, so that the Panel
will
>> be in a position to give some estimate of the potential risk for each
>> level
>> of dose. This would enable the consultant to identify any contactable
>> patients and to provide more informed risk estimates to any database
group
>> patients who indicate they would like to know. The Panel can carry out

assessments of the possible risks for all potentially exposed
> > patients once the necessary information is provided.
> >
> > 3. The Panel appreciates your desire to be open with haemophilia
> > patients
> > but asks you to consider whether it would be preferable to consult the
> > Panel first in order to provide the patients with the best informed
> > estimate of the potential risk that it is possible to carry out at
> > present.
> >
> > with regards
> >
> > Professor Michael Banner
> >
> > cc Recipients are reminded of the sensitive nature of CJD incidents and
> > asked not to discuss this incident with others.
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