

AAD Emato Oncologia Pediatrica

Direttore

Dr. Francesco Frassoni f.f

Oncologia Clinica

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To the Polish Oncology community

Oggetto: Polish Patients for the Immunotherapy treatment at the G. Gaslini Institute

Dear colleagues.

We have recently started treating an increasing number of patients from Poland affected by Neuroblastoma, who are referred to our Institute for the immunotherapy treatment.

In order for us to improve our cooperation in this complex and sensitive matter, I need to address a few important details on the procedures which will lead the polish patients' way to the G. Gaslini Institute:

- In all cases, referring physicians must include the patient's medical record, together with a summary of the patient's history, also the history of the performed treatment, and a copy of the passport or ID. It is important that you send us the preliminary documentation at least 2 months before the expected date of starting the GD2 treatment. Then, we will need you to confirm (one month before the actual admission)the appointment date for the first full-evaluation visit (a full week from Monday to Monday if possible)in our day hospital. That will also be the right time for the family to ask for help in finding a convenient accommodation nearby the hospital (The family will have to pay separately for this, but our social service will help in finding accommodation at a reasonable price and close to the hospital).

The treatment will be planned for approximately 2 weeks after the first full-evaluation visit. According to the current HR protocol, the first cycle requires 6-7 days of admission in ward, or 17-19 days in case it is the long term infusion protocol .

In the HR protocol, the 5 cycles will be administered with a 3 weeks interval (2 weeks on oral cis retinoic therapy, 1 week of rest),during which only standard blood tests are required.

In the LTI protocol, the 5 cycles will be administered in 17-day intervals of cis retinoic acid therapy, and some dedicated blood tests are required so the patient must remain near our center.

- All requests for second opinions and/or patient referrals must be addressed to:

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- In all cases, referring physicians must include the patient's medical record, together with a summary of the patient's history, also the history of the performed treatment, and a copy of the passport or ID. It is important that you send us the preliminary documentation at least 2 months before the expected date of starting the GD2 treatment. Then, we will need you to confirm (one month before the actual admission)the appointment date for the first full-evaluation visit (a full week from Monday to Monday if possible)in our day hospital. That will also be the right time for the family to ask for help in finding a convenient accommodation nearby the hospital (The family will have to pay separately for this, but our social service will help in finding accommodation at a reasonable price and close to the hospital). The treatment will be planned for approximately 2 weeks after the first full-evaluation visit. According to the current HR protocol, the first cycle requires 6-7 days of admission in ward, or 17-19 days in case it is the long term infusion protocol. In the HR protocol, the 5 cycles will be administered with a 3 weeks interval (2 weeks on oral cis retinoic therapy, 1 week of rest),during which only standard blood tests are required. In the LTI protocol, the 5 cycles will be administered in 17-day intervals of cis retinoic acid therapy, and some dedicated blood tests are required so the patient must remain near our center.
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International Patient's Office Istituto Giannina Gaslini e-mail: accoglienzavasconcelos@ospedale-gaslini.ge.it / GiovannaTamborra@ospedale-gaslini.ge.it fax: 0039-010-380432

with a copy to me

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fax: 0039 01056362714 tel.0039 010 56362694-410

- Requests from parents/guardians or from the Poland Ministry of Health must be addressed as above, and should also include a treatment's estimation request for all diagnostic and therapeutic procedures for the underlying disease.
- We will prepare together with our Institute's Billing Office an estimation of the costs for the patient's treatment. We will then send the estimated costs to the person or organization who made the original request. Regarding such costs, we decided to give you a fixed and discounted rate.

At the beginning we were applying the Italian government index (DRG)for general chemotherapy (such costs were around \in 20.000 Euros). However, the actual costs of this experimental therapy is about \in 50.000 Euros, and we would not be able to keep up with our cooperation for much longer if we were to charge less than 50% of the treatment's real costs. Therefore, we decided to come up of the total amount of \in 39.000 Euros for each polish patient, being \in 2.000 Euros for the first and last evaluation visits, and \in 7.000 Euros for each cycle. The first \in 2.000 should be paid in advance, while 1/3 of the total costs should be paid before the treatment effectively starts. The remaining amount should be paid after the last immunotherapy cycle at the patient's discharge, and If for any reason, the treatment does not reach its finish (i.e. the 5 cycles) any amount paid in excess will be refunded.

The above-mentioned treatment's cost includes medicines to take home, and room and board for one accompanying person during hospitalization. However, we are not able to support the stay of a second family member, nor are we able to support the accommodation for the family while staying in Genoa but not hospitalized. Our social workers will be able to help finding convenient alternatives for accommodation, but still the family will have to take care of such costs.

It is important to point out that complications will be charged separately, using the Italian government index (DRG)

Please be also aware that even if we are already mentioning the treatment's costs before hand, the contact person or contact organization still need to file the treatment' estimation request, so as to clear our administrative procedures

Important to notice that the average costs of living costs in Genoa (accomodation and meals) amount to approximately 1.000/1.200 Euros per month.

I hope that we were exhaustive enough in this letter so that everything regarding treating your patients here with us is clear. In any case, you have any further problems or experience administrative difficulties, please feel free to contact us and we will do our best to come up with a solution.

With my warmest regards

Alberto Garaventa

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