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SMA

acronimo
malattia
malati
famiglie

Anita Pallara – famiglie SMA

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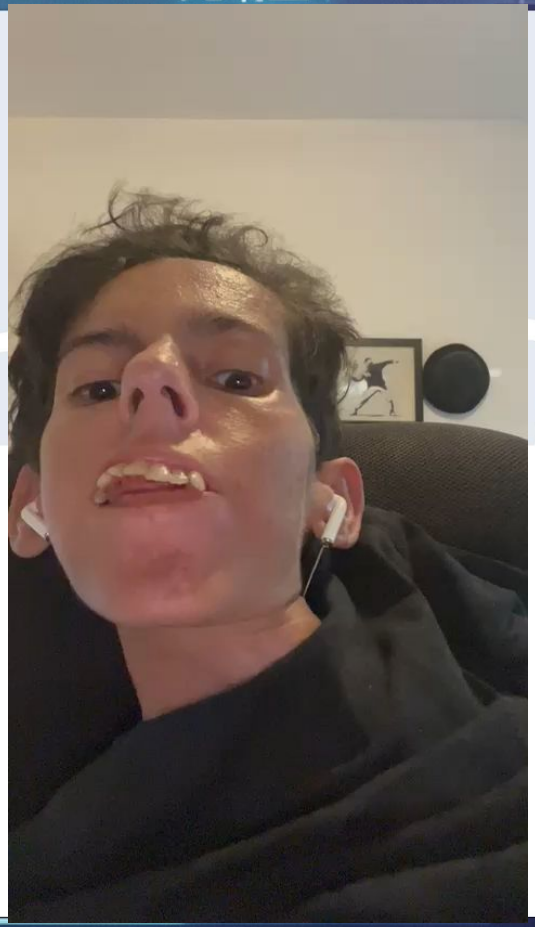

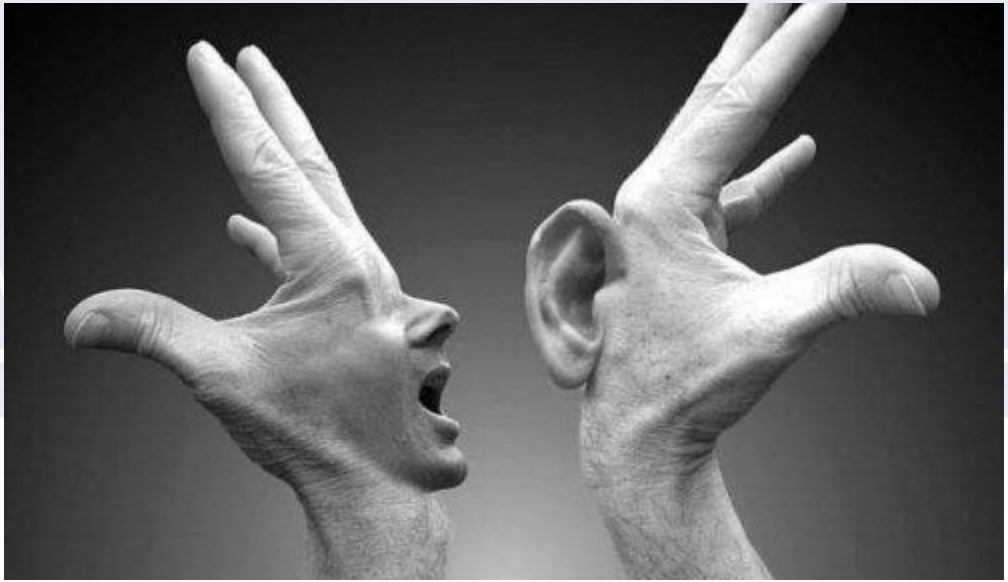

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venirsi incontro

umanizzazione delle cure

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costruire insieme nuovi percorsi

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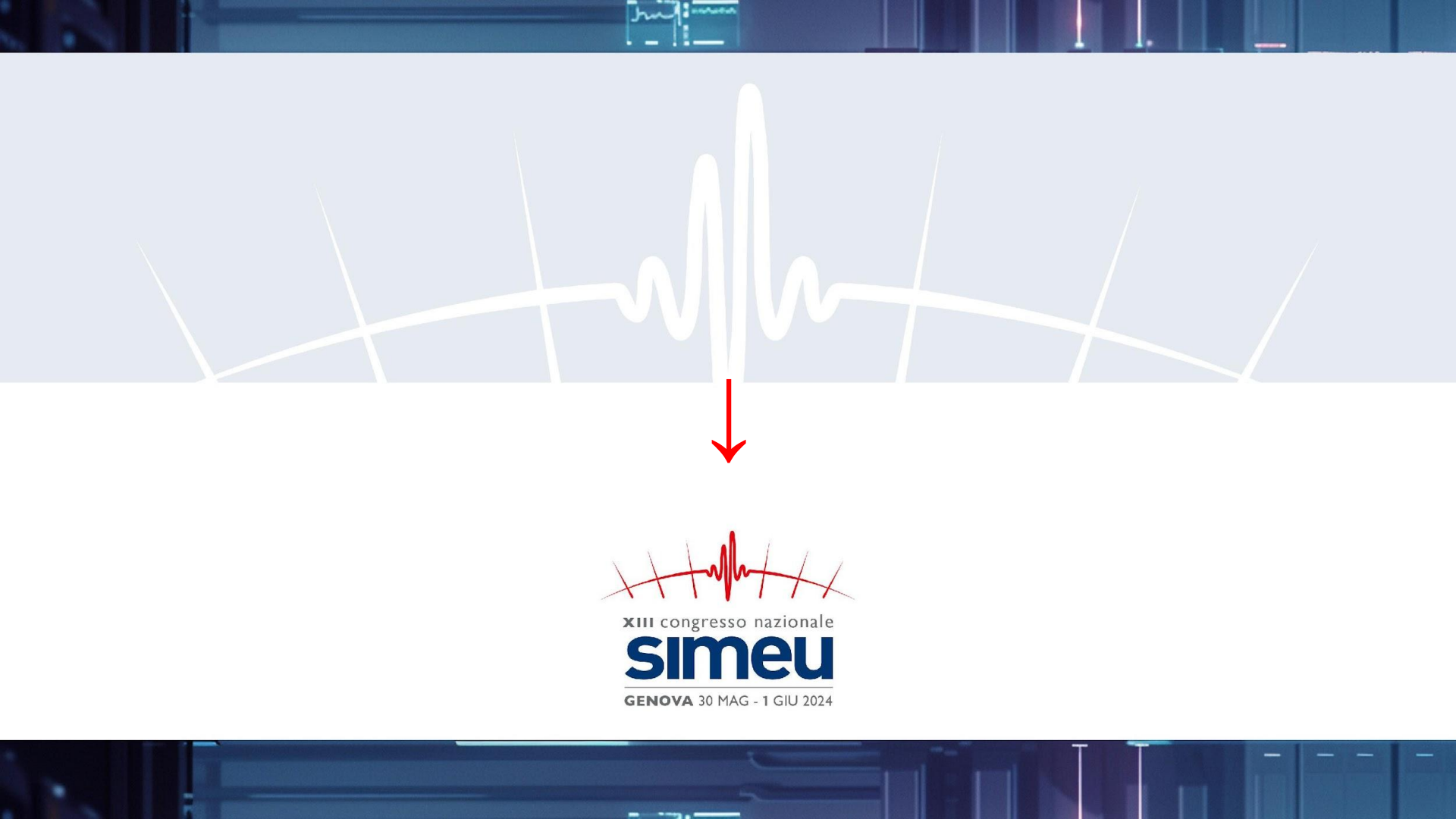
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SPECIAL ARTICLE

Managing emergency and urgent care in spinal muscular atrophy

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The multidisciplinary approach and the active involvement of various professional figures have substantially improved the quality of life of people affected by spinal muscular atrophy (SMA) and given them the possibility of carrying out activities and tasks on a daily basis.

New therapies, which have made it possible to reach survival rates never achieved before, have however opened up new challenges concerning psycho-social needs, the transition into adulthood and the management of health emergencies. These aspects were once considered less but are now increasingly topical and important.

A group of experts was set up to address and propose actions aimed at improving the experience of patients with SMA in Emergency Departments, including representatives of patients and specialists from different backgrounds. The work of the group of experts has resulted in a brief guide with crucial recommendations for the Emergency and Urgent Care setting. The objective is twofold: on the one hand, to improve the ER experience for patients affected by SMA and on the other to make ER staff aware of the clinical and care needs of these patients. ER physicians can play a crucial role in identifying potential risks/exacerbating factors, as well as in taking timely action to effectively avoid the progression of complications in patients with SMA.

Current knowledge

The effectiveness of new therapies for SMA management is now widely demonstrated in clinical trials as well as in real life.[1] The results obtained thanks to innovative drugs have opened up the way to addressing the needs of these patients in their daily life that will tend to be increasingly similar to that of the population not affected by SMA.

These needs also include the management of emergencies that require access to the ER. Patients with SMA are particularly vulnerable and subject to respiratory tract infections,[2] and other manifestations (*e.g.*, pain, gastrointestinal pathologies, fractures) can occur with a certain frequency and require access to the ER for care.[3]

The hospitals where emergency patients with

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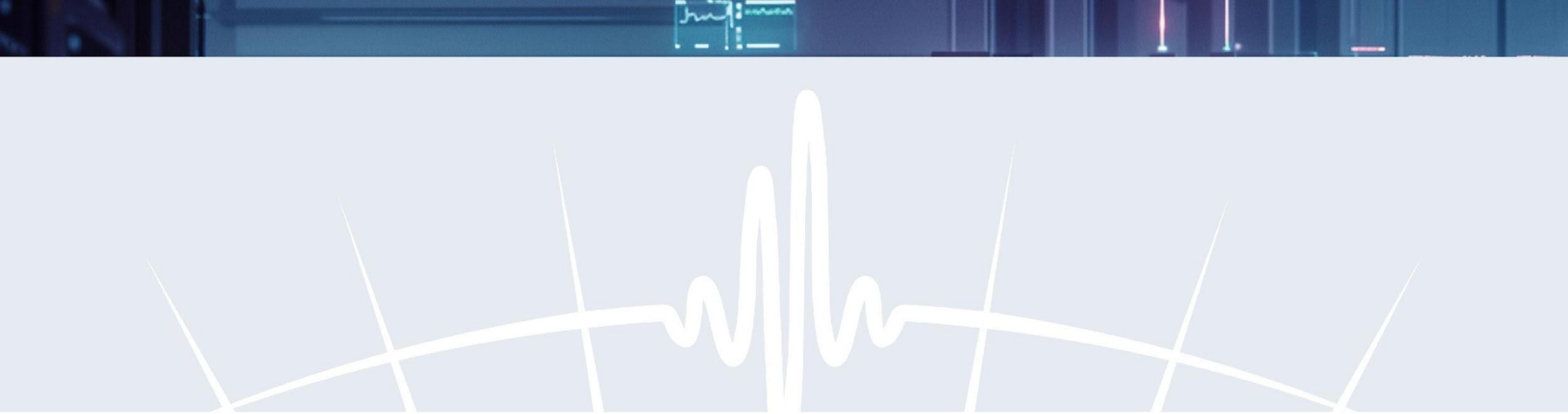

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progetto che potremmo definire
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