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#### REQUESTS ADDRESSED TO THE ADVISORY COMMITTEE STEMMING FROM HUMAN RIGHTS COUNCIL RESOLUTIONS: RIGHT TO FOOD

"The tragedy of Noma"

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#### Introduction

1. In its resolution from 20 March 2009, the Human Rights Council requested the Advisory Committee:

"to undertake a study on discrimination in the context of the right to food, including identification of good practices of anti-discriminatory policies and strategies, and to report on it to the thirteenth session of the Human Rights Council".<sup>1</sup>

2. This background paper on the right to food and the noma disease has been undertaken within the framework of anti-discrimination, as requested by the Human Rights Council. This background paper has been written with the intention of contributing to the full study that the Advisory Committee will undertake on discrimination in the context of the right to food.

3. In Section I of this background paper, we briefly present the legal framework of the right to food and the non-discrimination clause with special reference to vulnerable groups. In the subsections, relevant aspects related to the noma disease such as causes and treatment are put forward. Furthermore, the impact of the food and economic crisis on vulnerable groups is discussed, with particular attention to the link between the right to food and noma. Lastly, the responses of the international community to noma, as well as the problematic aspects are outlined. Section II proposes recommendations on measures to be taken by States and the Human **Rights Council.** 

## I. THE RIGHT TO FOOD AND THE NOMA DISEASE

4. The right to food is a human right protected by human rights norms and international humanitarian law. Article 11 of the International Covenant on Economic, Social and Cultural Rights proclaims the right to an adequate standard of living, including adequate food, and the fundamental right of everyone to be free from hunger.<sup>2</sup>

Hunger has been defined by the Task Force on Hunger of the UN Millennium Project as 5. occurring in three forms: acute, chronic and hidden. Whereas acute hunger remains the most publicized, the majority of the globe's hungry experience chronic undernourishment and malnutrition.<sup>3</sup> Malnutrition, also called the hidden hunger, is a state of nutrition in which deficiency of calories, proteins or nutrients causes adverse effects on tissue and/or body functions.<sup>4</sup> Thus, malnutrition necessarily encompasses undernourishment and acute hunger, given that a person that does not receive enough food is also not fed adequately in terms of nutrients.<sup>5</sup> Nonetheless, a person does not necessarily need to be undernourished for malnutrition to exist – it might be that the person receives enough calories but not enough nutrients.<sup>6</sup>

<sup>&</sup>lt;sup>1</sup> Human Rights Council, The Right to Food, A/HRC/10/L.25, 20 March 2009.

<sup>&</sup>lt;sup>2</sup> International Covenant on Economic, Social and Cultural Rights, Art. 11(1) and (2).

<sup>&</sup>lt;sup>3</sup> UN Millennium Project, Task Force on Hunger, Halving Hunger: It Can Be Done, 2005, p. 2.

<sup>&</sup>lt;sup>4</sup> Michael J. Gibney, Marinos Elia, Olle Ljungqvist, Julie Dowsett, Clinical Nutrition, (Wiley-Blackwell, 2005), pp. 1-2.

Christophe Golay, Droit à la alimentation et accès a la justice, (Genève: Université de Genève et IHEID, 2009), p. 58. <sup>6</sup> Ibid.

6. In its General Comment No. 12 (1999) – which has become recognized as the authoritative interpretation of the right to food<sup>7</sup> – the Committee on Economic, Social and Cultural Rights takes into consideration all three forms of hunger. The Committee affirms that "the right to adequate food is realized when every man, woman and child, alone or in community with others, has physical and economic access at all times to adequate food or means for its procurement".<sup>8</sup> Inspired by this definition, the right to food has been defined by the former Special Rapporteur on the Right to Food as: "the right to have regular, permanent and unrestricted access, either directly or by means of financial purchases, to quantitatively and qualitatively adequate and sufficient food corresponding to the cultural traditions of the people to which the consumer belongs, and which ensures a physical and mental, individual and collective, fulfilling and dignified life free of fear."

7. The Committee on Economic, Social and Cultural Rights and the special rapporteurs on adequate food have underlined the particular attention that needs to be paid to the most vulnerable individuals and groups and their access to food which should satisfy their dietary needs.<sup>10</sup> Both socially vulnerable and physical vulnerable groups are specifically mentioned in the Committee's General Comment 12.<sup>11</sup> Guideline 13 of the Right to Food Guidelines, adopted by the FAO member states in November 2004, recommends establishing food insecurity and vulnerability maps and the use of disaggregated data to identify "any form of discrimination that may manifest itself in greater food insecurity and vulnerability to food insecurity, or in a higher prevalence of malnutrition among specific population groups, or both, with a view to removing and preventing such causes of food insecurity or malnutrition.<sup>12</sup> Along these lines, identification of vulnerable groups and action towards removing the factors determining vulnerability are an integral part of the general anti-discrimination requirement in human rights law, and implicit in the right to food.

8. Children living in poverty are probably the best exemplification of a social and physical vulnerable group. In addition to the above instruments and interpretations that address adults as well as children, the Convention on the Rights of the Child is highly relevant in the case at hand. Article 24 of this most widely ratified human rights instrument provides that States shall take appropriate measures to combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water.<sup>13</sup>

9. Whereas the legal framework of the right to food is clearly established at the international level, in practice, the noma disease ravages children in several parts of the world. The mere existence of this disease demonstrates that the right to food of the most vulnerable is being violated.

<sup>&</sup>lt;sup>7</sup> Ibid.

<sup>&</sup>lt;sup>8</sup> Committee on Economic, Social and Cultural Rights, General Comment 12, 1999, para 6.

<sup>&</sup>lt;sup>9</sup> Report of the Special Rapporteur on the Right to Food, Jean Ziegler, A/HRC/7/5, para. 17, 10 January 2008.

<sup>&</sup>lt;sup>10</sup> Committee on Economic, Social and Cultural Rights, *supra* note 8, and see for example Report of the Special Rapporteur on the Right to Food, Jean Ziegler, A/HRC/4/30, 19 January 2007; Report of the Special Rapporteur on the Right to Food, Jean Ziegler, A/62/289, 22 August 2007; Report of the Special Rapporteur on the Right to Food, Olivier de Schutter, A/HRC/9/23, 8 September 2008.

<sup>&</sup>lt;sup>11</sup> Committee on Economic, Social and Cultural Rights, *supra* note 8.

<sup>&</sup>lt;sup>12</sup> Voluntary Guidelines to Support the Progressive Realization of the Right to Adequate Food in the Context of National Food Security, Guideline 13.

<sup>&</sup>lt;sup>13</sup> Convention on the Rights of the Child, Article 24.

#### A. The characteristics of noma

Noma (cancrum oris), which borrows its name from the Greek term "to devour", is a 10. devastating infectious disease that destroys the soft and hard tissue of the face.<sup>14</sup> The lesion begins as a localized ulceration in the gingiva or the mucosa of the cheek or lip and spreads rapidly through the orofacial tissues.<sup>15</sup> Untreated, the skin of the cheek or lip is typically perforated within a week of the start of the swelling. The gangrene of the facial tissue quickly spreads to other parts of the face such as the nose or an eye, leaving a terrible hole in the face.<sup>16</sup> Noma leads to gangrene, sepsis and in 70-90% of cases, death.<sup>17</sup> Most deaths are attributed to complications such as pneumonia, diarrhoea and septicaemia associated with severe malnutrition.<sup>18</sup>

Survivors suffer threefold: disfigurement, functional impairment and social stigma. 11. Doctors describe the restriction of the jaw movement and the loss of part of the maxilla, mandible or other facial bones as the usual consequences of noma.<sup>19</sup> Without reconstructive surgery, tragically, "[a] child who survives is unlikely ever to be able to speak or eat normally again."20

The clinical data available is unanimous: children are the main victims of this debilitating 12. disease. Acute noma occurs predominantly in malnourished children aged 1 and 6 years,<sup>21</sup> while late stages have been observed in adolescents and adults.<sup>22</sup> Having studied patients with noma in Nigeria, Phillips et al, conclude that noma is not observable in children of "elite Nigerians residing in affluent sections of the urban areas" and that "[i]t is rather a socioeconomic disease afflicting preferentially the deprived, malnourished children in the poor, rural communities".<sup>23</sup> Medical studies concur on the specific population group that is predominantly affected by noma:

<sup>&</sup>lt;sup>14</sup> Midion Mapfumo Chidzonga and Leonard Mahomva, "Noma (Cancrum Oris) in Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome (HIV and AIDS): Clinical Experience", Journal of Oral & Maxillofacial Surgery, August 2008, p. 475; Cyril O Enwonwu, William A Falkler Jr, Reshma S Phillips, "Noma (cancrum oris)", The Lancet, p. 147.

<sup>&</sup>lt;sup>15</sup> Kurt Bos, Klass Marck, *The Surgical Treatment of Noma*, (Alphen aan den Rijn: Belvedere/Medidac, 2006), p. 13 <sup>16</sup> Ibid., p. 14; M. Leila Srour, Bryan Watt, Bounthom Phengdy, Keutmy Khansoulivong, Jim Harris, Christopher Bennett, Michel Strobel, Christian Dupuis, and Paul N. Newton, "Noma in Laos: Stigma of Severe Poverty in Rural Asia", American Journal of Tropical Medicine and Hygiene, 78(4), 2008, p. 539. <sup>17</sup> WHO/AFRO, Noma Programme in the African Region, <u>http://www.afro.who.int/noma/introduction.html</u>

<sup>&</sup>lt;sup>18</sup> D.E.Barmes, C.O.Enwonwu, M-H.Leclercq, D.Bourgeois and W.A.Falkler, "The need for action against orofacial gangrene (noma)", Tropical Medicine and International Health, 2 (12), 1997, p. 1113. <sup>19</sup> Ibid.

<sup>&</sup>lt;sup>20</sup> Ibid.

<sup>&</sup>lt;sup>21</sup> The European Noma-Network, <u>http://www.noma-project.de/htmlversion/indexhtml.html;</u> Denise Baratti-Mayer, Brigitte Pittet, Denys Montandon, Ignacio Bolivar, Jacques-Etienne Bornand, Stéphane Hugonnet, Alexandre Jaquinet, Jacques Schrenzel, Didier Pittet, "Noma: an "infectious" disease of unknown aetiology", The Lancet *Infectious Diseases*, 3 July 2003, p. 420. <sup>22</sup> Cyril O Enwonwu, William A Falkler Jr, Reshma S Phillips, *supra* note 14, p. 147.

<sup>&</sup>lt;sup>23</sup> Reshma S. Phillips, Cyril O. Enwonwu, William A. Falkler, "Pro- versus anti-inflammatory cytokine profile in African children with acute oro-facial noma (cancrum oris, noma)", European Cytokine Network, 16 (1), March 2005, p. 70.

deprived and severely malnourished young children from communities living in extreme poverty.<sup>24</sup>

## **1.** History of the disease

According to Klaas Marck, who undertook a comprehensive research project on the 13. history of noma, the disease was already known in classical and medieval Europe.<sup>25</sup> Already in the 18<sup>th</sup> century, awareness that noma is related to poverty, malnutrition and preceding diseases such as measles increased in Northwestern Europe.<sup>26</sup> Noma remained common in Europe and North America until the beginning of the 20<sup>th</sup> century. However, it is widely held that before the discovery of penicillin, the disease had almost disappeared from European and North American societies. The economic progress witnessed by these societies is credited with having allowed them to feed their children sufficiently and hence to practically eradicate noma.<sup>27</sup> Cases of noma reappeared in the Nazi concentration camps of Bergen-Belsen and Auschwitz<sup>28</sup> and in some other European countries subjected to extreme food shortages during the World War II.<sup>29</sup> More recently, the disease has been documented in patients with HIV infection or AIDS from developed States.<sup>30</sup> A 2006 study reports the recent case of a 68-year old retired man from the United Kingdom who had noma. The doctors who treated the man conclude that debilitated individuals in the developed world suffering of malnourishment, bad oral hygiene and immunosuppression may also be at risk, despite the predominance of the disease in malnourished children of developing countries.<sup>31</sup> The above comes to prove that noma is not a tropical disease, but a poverty related disease.<sup>32</sup>

## 2. Incidence of noma

14. A 2008 World Health Organization (WHO) study, cites the low- and middle-income countries, particularly in Africa and Asia, as the most affected by noma.<sup>33</sup> It is assumed that the majority of individuals affected by noma live in the sub-Saharan countries of Mauritania, Senegal, Mali, Niger, Nigeria, Chad, Sudan and Ethiopia.<sup>34</sup> Experts, including NGOs, working in the field, describe the area that stretches across parts of West Africa, Central Africa towards

<sup>&</sup>lt;sup>24</sup> Cyril O. Enwonwu, "Noma-The Ulcer of Extreme Poverty", *The New England Journal of Medicine* 354 (3), January 2006; M. Leila Srour et al, *supra* note 16, p. 539; WHO, *Acting against Disease: Open the Mouth of Your Children*, <u>http://www.afro.who.int/noma/acting\_against\_noma.pdf</u>

<sup>&</sup>lt;sup>25</sup> Klass Marck, "A History of Noma, the "Face of Poverty", *Plastic and Reconstructive Surgery*, 111(5), April 2003.

<sup>&</sup>lt;sup>26</sup> Ibid.

<sup>&</sup>lt;sup>27</sup> Roeland Voorhoeve, "Review", *Bulletin of the Netherlands Society of Tropical Medicine and International Health*, 49 (1), February 2008, p. 13; Cyril O. Enwonwu, *supra* note 24; Cyril O Enwonwu, William A Falkler Jr, Reshma S Phillips, *supra* note 14, p. 148.

<sup>&</sup>lt;sup>28</sup> Cyril O Enwonwu, William A Falkler Jr, Reshma S Phillips, *supra* note 14, p. 148.

<sup>&</sup>lt;sup>29</sup> Kurt Bos, Klaas Marck, *supra* note 15, p. 11.

<sup>&</sup>lt;sup>30</sup> Cyril O. Enwonwu, William A. Falkler Jr, Reshma S. Phillips, *supra* note 14, p. 148.

<sup>&</sup>lt;sup>31</sup> A. G. Buchanan, M. Cedro, A. Mirdin, T. Joseph, S. R. Porter and T. A. Hodgson, "Necrotizing stomatitis in the developed world", *Clinical and Experimental Dermatology* 31, 2006, p. 372.

<sup>&</sup>lt;sup>32</sup> Roeland Voorhoeve, *supra* note 27, p. 13.

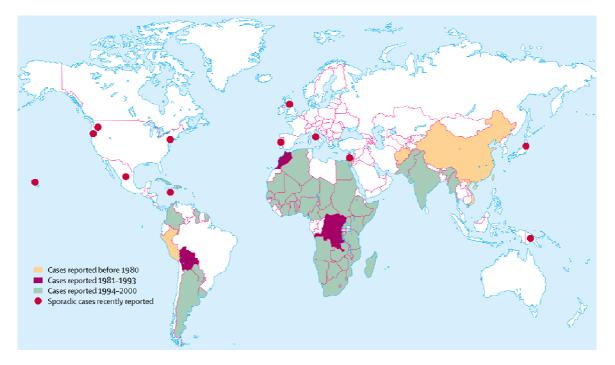
<sup>&</sup>lt;sup>33</sup> Poul Erik Petersen, "World Health Organization global policy for improvement of oral health – World Health Assembly 2007", *International Dental Journal* (2008) 58, p. 117.

<sup>&</sup>lt;sup>34</sup> Kurt Bos, Klaas Marck, *supra* note 15, p. 12; Cyril O. Enwonwu, William A. Falkler Jr, Reshma S. Phillips, *supra* note 14, p. 148.

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Sudan as the "noma belt".<sup>35</sup> Cases are reported from other countries in Africa, Asian and Latin American<sup>36</sup>, as Figure 1 shows. A recent medical paper on noma in Laos concludes that "it is likely that it is much more frequent in remote Asian rural communities than is currently appreciated."37

According to estimates released by WHO in 1998, 140 000 individuals contract noma on 15. a yearly basis<sup>38</sup>, 100 000 of these being children aged between 1 and 7 years and living in sub-Saharan Africa.<sup>39</sup> The survival rate is between 10 and 30 %, which means that at least 100 000 people, the vast majority of which are children, die every year because of noma.<sup>40</sup> According to the WHO report, as of 1997, 770 000 persons survived the disease with heavy sequelae.<sup>41</sup>



# Figure 1 – Global distribution of reported cases of noma<sup>42</sup>

<sup>&</sup>lt;sup>35</sup> Consultative Meeting on Management of the Noma Programme in the African region, Final Report, Harare, 19-21 2001: "What Zimbabwe. April Facing Africa. is noma?". http://www.facingafrica.org/FA08/content/site/en/pages/whatisnoma/default.asp. <sup>36</sup> Kurt Bos, Klaas Marck, *supra* note 15, p. 12.

<sup>&</sup>lt;sup>37</sup> M. Leila Srour et al, *supra* note 16, p. 540.

<sup>&</sup>lt;sup>38</sup> WHO, The World Health Report 1998 - Life in the 21st century: A Vision for all, Geneva, 1998, p. 45.

<sup>&</sup>lt;sup>39</sup> Brad Neville, Douglas D. Damm, Carl M. Allen, Jerry E. Bouquot, Oral and Maxillofacial Pathology, 3rd Edition, (Elsevier Health Sciences, 2008), p. 201.

<sup>&</sup>lt;sup>40</sup> The WHO study puts the number of death at 110000, i.e. 79%. WHO, supra note 38, p. 45; Other sources cite either the range 70-80% or 90%, see Cyril O. Enwonwu, supra note 24; Kurt Bos, Klaas Marck, supra note 15, p. 13; Denise Baratti-Mayer et al, supra note 8, p. 421.

<sup>&</sup>lt;sup>41</sup> WHO, supra note 38, p. 45; Alexander Fieger, Klaas W. Marck, Raymonde Busch and Andreas Schmidt, "An estimation of the incidence of noma in north-west Nigeria", Tropical Medicine and International Health, 8 (5), May 2003, p. 402.

<sup>&</sup>lt;sup>42</sup> The map was adapted from WHO by Cyril O. Enwonwu, William A. Falkler Jr, Reshma S. Phillips, *supra* note 14, p. 148.

More recent data has been calculated in 2003 based on information from patients which 16. have been admitted with the noma disorder in two hospitals in Sokoto, Nigeria.<sup>43</sup> By extrapolating the incidence from Northwestern Nigeria to the countries bordering the Sahara Desert it showed an annual incidence of 25 600 cases for that region and a global incidence per year of 30 000 – 40 000.<sup>44</sup> Experts consider this data to be rather conservative, given that less than 10% of the individuals suffering of noma seek medical care.<sup>45</sup> In the suggestive words of Cyril O. Enwonwu, these cases represent merely "the tip of the iceberg".<sup>46</sup>

The distribution of acute noma across the globe remains uncertain, which in turn leads to 17. the tragic situation that the majority of children and other individuals with noma are not receiving treatment. There are several factors of different nature that contribute to the lack of accurate global data.<sup>47</sup> Firstly, WHO standardized the registration of noma only in 1992, and developing countries started to report noma cases only in 1994.<sup>48</sup> Some experts note the inadequacy of health records in general.<sup>49</sup> Others note the difficulty of keeping such records when the patients are children from communities with a nomadic lifestyle. 50 Given the high mortality rate associated to this disorder, many cases of acute noma remain undiscovered.<sup>51</sup> In addition, health systems in countries where noma predominantly occurs are considered to be usually unsuited for treating a disease with such a rapid development.<sup>52</sup> Lack of knowledge or information about the clinical signs and preventive treatment provided to health personnel adds to the situation.<sup>53</sup> The stigma aspect that is associated to this terrible disease should also be taken into consideration. Because of a lack of appropriate information for the population in general and mothers in particular, noma tends to be perceived as curse or as shame on the family whose child contracts it. It is certainly a powerful taboo that causes families to sometimes hide or isolate their children whose faces are disfigured by this disease with animals.<sup>54</sup> Furthermore, experts in the field have reported that noma is ignored and neglected by political authorities.

<sup>48</sup> Denise Baratti-Mayer *et al, supra* note 8, p. 421.

<sup>49</sup> D.E.Barmes, C.O.Enwonwu, M-H.Leclercq, D.Bourgeois and W.A.Falkler, see *supra* note 18, p. 1111.

<sup>50</sup> Cvril O. Enwonwu, *supra* note 24.

<sup>&</sup>lt;sup>43</sup> Alexander Fieger et al, supra note 41, p. 403.

<sup>&</sup>lt;sup>44</sup> *Ibid*, p. 402.

<sup>&</sup>lt;sup>45</sup> Cyril O. Enwonwu, supra note 24; Denise Baratti-Mayer et al, supra note 8, p. 421; M. Leila Srour et al, supra note 16, p. 539.

<sup>&</sup>lt;sup>46</sup> Cyril O. Enwonwu, supra note 24; see also Rapport de la 5ème Table Ronde sur le Noma, Genève, 9 septembre 2006, http://www.afro.who.int/noma/table ronde noma 2006.pdf.

<sup>&</sup>lt;sup>47</sup> Writing in 2006, Cyril O. Enwonwu, William A. Falkler Jr, Reshma S. Phillips, refer back to studies from the late 1990s for the explanatory factors regarding the uncertainty of data on the global incidence of noma. This proves that the factors cited by the older studies remain unfortunately accurate to this day. Cyril O. Enwonwu, William A Falkler Jr, Reshma S Phillips, supra note 14, p. 147.

<sup>&</sup>lt;sup>51</sup> Ibid; DM Bourgeois, MH Leclercq, "The World Health Organization Initiative on Noma", Oral Diseases 5 (1999), p. 172. <sup>52</sup> DM Bourgeois, MH Leclercq, *supra* note 51, p. 173.

<sup>&</sup>lt;sup>53</sup> Ibid, pp. 172-3; M. Leila Srour argues that only few doctors in Asia are aware of noma and that probably they would not recognize it because it has rarely been described as a disease present on the Asian continent. M. Leila Srour et al, supra note 16, p. 540.

<sup>&</sup>lt;sup>54</sup> DM Bourgeois, MH Leclercq, *supra* note 51, p. 173; Denise Baratti-Mayer *et al*, *supra* note 8, p. 421.

#### **3.** Causes and predisposing factors

18. As yet, researchers have not identified a specific microorganism responsible for causing noma.<sup>55</sup> Despite the lack of certainty in respect to the microbiology and pathophysiology, there is a wide consensus among experts that noma results from the interaction between three main elements: malnutrition, intraoral infections and compromised immunity.<sup>56</sup>

19. Malnutrition is considered to be the major predisposing factor for noma.<sup>57</sup> Experts describe malnutrition as the necessary pre-condition for noma to appear.<sup>58</sup> The absence of noma cases in well-nourished African children, associated with the occurrence of the illness in Nazi concentration camps where malnourishment was rampant, strongly supports the evidence that malnutrition plays a significant role in the development of this disease.<sup>59</sup> In the words of Enwonwu et al: "The global distribution pattern of the disease reflects the worldwide distribution of malnutrition".<sup>60</sup> Along these lines, protein-energy malnutrition, occurring often in congruence with deficiencies of vitamins (in particular vitamin A and B) and minerals are the most frequently observed in children at risk of noma.<sup>61</sup>

20. Recent research is inquiring into the relevance of pre-natal malnutrition for the contraction of noma. In several countries where noma has been documented, malnutrition is said to commence *in utero* as a consequence of poor maternal nutrition, and result in intrauterine growth retardation and low birth weight.<sup>62</sup> In early post-natal life, and often extending through adolescence into adulthood, the latter have as consequence chronic malnutrition and a diminished resistance to infections.<sup>63</sup> These in turn are key contributing elements to the development of noma.

21. Research has shown that a high bacterial load of normal microorganisms from the mouth breaks the resistance of a failing immune system.<sup>64</sup> *Fusobacterium necrophorum* and *Prevotella intermedia* are thought to be key players in this process in which components of the normal oral flora become pathogenic.<sup>65</sup> As mentioned above, the weakening of the immune system due to infections (such as measles, malaria, tuberculosis, typhus, HIV) and poor oral hygiene (specifically the presence of acute necrotizing gingivitis<sup>66</sup>) can contribute to the development of

<sup>&</sup>lt;sup>55</sup> Reshma S. Phillips, Cyril O. Enwonwu, William A. Falkler, "Pro- versus anti-inflammatory cytokine profile in African children with acute oro-facial noma (*cancrum oris*, noma)", *European Cytokine Network*, 16 (1), March 2005, p. 70.

<sup>&</sup>lt;sup>56</sup> Alexander Fieger *et al, supra* note 41, p. 402; Cyril O. Enwonwu, William A. Falkler Jr, Reshma S. Phillips, *supra* note 14, p. 147; Cyril O. Enwonwu, *supra* note 24; Interview de Bertrand Piccard, « Notre nouveau but : mettre sur pied une Journée mondiale contre le noma », *Tribune Medicale*, 29 septembre 2006.

<sup>&</sup>lt;sup>57</sup> Ibid; Cyril O Enwonwu, William A Falkler Jr, Reshma S Phillips, supra note 14, p. 152.

<sup>&</sup>lt;sup>58</sup> D.E. Barmes, C.O. Enwonwu, M-H. Leclercq, D. Bourgeois and W.A. Falkler, see *supra* note 18, p. 1111.

<sup>&</sup>lt;sup>59</sup> Cyril O Enwonwu, William A Falkler Jr, Reshma S Phillips, *supra* note 14, p. 151.

<sup>60</sup> Ibid.

<sup>&</sup>lt;sup>61</sup> D.E. Barmes, C.O. Enwonwu, M-H. Leclercq, D. Bourgeois and W.A. Falkler, see *supra* note 18, p. 1111-2.

<sup>&</sup>lt;sup>62</sup> C. O. Enwonwu, "Ruminations on the causation of noma", *Stomatolgie*, 104 (1), März 2007, pp. 43-4.

<sup>&</sup>lt;sup>63</sup> Ibid.

<sup>&</sup>lt;sup>64</sup> Alexander Fieger *et al*, *supra* note 41, p. 402.

<sup>&</sup>lt;sup>65</sup> Brad Neville et al, supra note 39, p. 201; see also M. Leila Srour et al, supra note 16, p. 539.

<sup>&</sup>lt;sup>66</sup> The present expert consensus is that acute necrotizing gingivitis is the precursor of noma. Denise Baratti-Mayer *et al, supra* note 8, p. 421; Paula Moynihan Poul Erik Petersen, "Diet, nutrition and the prevention of dental diseases", *Public Health Nutrition*, 7(1A), p. 203.

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the illness.<sup>67</sup> Other risk factors, which are often cited by specialists, are unsafe drinking water and dehydratation, poor sanitation and close proximity to unkempt livestock.<sup>68</sup>

## 4. The treatment of noma

22. The WHO identifies four stages of the disease; noma can reach its terminal phase in the extremely short time span of three weeks.<sup>69</sup> In the early stage, when the gingiva is bleeding and has lesions, impending noma can be treated in a manner which is "simple, effective, low-cost"<sup>70</sup> with disinfecting mouth-rinses and daily food with vitamins.<sup>71</sup> During the next phase, involving swelling of the face and fever, mouth-rinses, administration of antibiotics and nutrients supplementation is essential.<sup>72</sup> These have been shown to prevent the progression from the initial ulceration to the acute phases of the disease, which presuppose emergency care and reconstructive surgery.<sup>73</sup>

23. As was noted in a previous section, the death rate associated to noma is spectacular high. However if recognized early and treated correspondingly with oral hygiene, antibiotics and nutritious feeding, the mortality can to drop from 70-90% to approximately 20%.<sup>74</sup> Hence, early recognition of the clinical signs of this disorder is critical for its treatment.

24. Addressing the risk factors of noma represents a means of preventing and curing the disease. Experts underline the remarkable overlap between places on the world map with high mortality because of noma, low vaccination against measles and extreme poverty.<sup>75</sup> For example, in Northwest Nigeria measles immunization coverage is close to zero; at the same time this area is considered the epicenter of noma.<sup>76</sup> Vaccination against infections such as measles that weaken the immune system would considerably cut the incidence of noma.<sup>77</sup>

25. Improving the diet of malnourished children in risk areas could considerably lower the death rate and occurrence of this disorder. Bertrand Piccard, the founder of the organization Winds of Hope and president of the No Noma - International Noma Federation, considers that "le vaccin contre le noma, ce serait de nourrir toute l'Afrique".<sup>78</sup> In more realistic terms, and in accordance with the Millennium Development Goals, Médecins sans Frontiers calculates that 2.74 billion Euro are needed to eliminate acute severe malnutrition of children.<sup>79</sup> Put in

<sup>&</sup>lt;sup>67</sup> Kurt Bos, Klaas Marck, *supra* note 15, p. 13.

<sup>&</sup>lt;sup>68</sup> Poul Erik Petersen, "World Health Organization Global Policy for Improvement of Oral Health – World Health Assembly 2007", *International Dental Journal* (2008) 58, p. 117.

<sup>&</sup>lt;sup>69</sup> WHO, "Acting against Disease", *supra* note 24.

<sup>&</sup>lt;sup>70</sup> Kurt Bos, Klaas Marck, *supra* note 15, p. 18.

<sup>&</sup>lt;sup>71</sup> WHO, "Acting against Disease", *supra* note 24.

<sup>&</sup>lt;sup>72</sup> Ibid; Kurt Bos, Klaas Marck, *supra* note 15, p. 18; M. Leila Srour *et al*, *supra* note 16, p. 539.

<sup>&</sup>lt;sup>73</sup> Ibid.

<sup>&</sup>lt;sup>74</sup> Kurt Bos, Klaas Marck, *supra* note 15, p. 18.

<sup>&</sup>lt;sup>75</sup> Alexander Fieger *et al*, *supra* note 41, p. 406.

<sup>&</sup>lt;sup>76</sup> Klaas W. Marck, "Measles vaccination would cut noma deaths", *Noma Contact*, WHO, p. 5.

<sup>&</sup>lt;sup>77</sup> *Ibid*.

<sup>&</sup>lt;sup>78</sup> Interview de Bertrand Piccard, *supra* note 56.

<sup>&</sup>lt;sup>79</sup> Action contre le Faim and Médecins sans Frontiers, *One Crisis May Hide Another: Food Price Crisis Masked Deadly Child Malnutrition*, 26-27 January 2009, p. 3, p. 7.

perspective, 2.76 billion Euro represents a truly insignificant fraction of the economic recovery plans which have been approved in the last months by governments throughout the globe.<sup>80</sup>

## B. The impact of the food and economic crisis

In the light of the experts' findings that malnutrition is the major predisposing factor of 26. noma, the impact of the recent food crisis and of the economic downturn on the incidence of this disease must be addressed. Following the more general pattern of paucity of data related to noma, there is no specific information available on noma in connection to the crises. However, statistics on undernourishment and malnutrition exist and based on these extrapolation on whether the risk of noma increased is feasible.

27. According to the Food and Agriculture Organization (FAO), as a result of the recent food crisis the number of chronically hungry people rose by 75 million in 2007, to reach a total of 923 million undernourished people.<sup>81</sup> Today's reality appears to be even bleaker than the one in 2007. A recent statement of the World Bank considers the number of undernourished to now exceed 1 billion.<sup>82</sup> Looking at this data in a disaggregated manner shows that 89% of the 923 million chronically hungry people live in Asia and the Pacific and Sub-Saharan Africa. These two regions have seen the greatest increase in undernourishment caused by the food crisis.<sup>83</sup> FAO indicates further that high prices of internationally traded commodities, such as staple grains and vegetable oils, are expected "to increase the prevalence of malnutrition among both urban and rural households", while noting that the most vulnerable groups are the ones from "countries with already low levels of dietary diversity."<sup>84</sup> Furthermore, evidence from past crises shows that when faced with worsening economic conditions and high food prices, poor families eat cheaper and less nutritious food, leading to malnutrition, especially for young children and pregnant women.<sup>85</sup>

28. Specifically in South Asia, the United Nations Children's Fund (UNICEF) puts the number of hungry people in 2009 at 400 million, up by 100 million from the already unacceptable figure of pre-crises days. Moreover, of the 175 million children under 5 years living in the region, 45% are malnourished. By any measure this is the highest rate of malnutrition in the world, "eclipsing even Sub-Saharan Africa."<sup>86</sup> This picture is even more worrisome as it is generally acknowledged that the GDP growth rates of South Asia are twice as high as those in Africa,<sup>87</sup> which means that surpluses during pre-crises years have not been used properly to tackle malnutrition of children.

29. Action contre le Faim and Médecins sans Frontiers submit that 55 million children are affected by acute malnutrition at any given moment and that 19 million of these suffer from the

<sup>&</sup>lt;sup>80</sup> The Economist estimates that states have spent around three trillion dollars on bank write-downs: "Three trillion dollars later...", The Economist, May  $16^{\text{th}} - 22^{\text{nd}} 2008$ .

<sup>&</sup>lt;sup>81</sup> FAO, The State of Food Insecurity in the World 2008: High Food Prices and Food Security – Threats and Opportunities, 2008, p. 6 <sup>82</sup> World Bank, World Bank Expands Response to Food Price Crisis to \$2 Billion, 21 April 2009.

<sup>83</sup> FAO, supra note 81, p. 7

<sup>&</sup>lt;sup>84</sup> Ibid.

<sup>&</sup>lt;sup>85</sup> UNICEF, A Matter of Magnitude: The Impact of the Economic Crisis on Women and Children in South Asia, June 2009, p. 7.

<sup>&</sup>lt;sup>86</sup> Ibid, p. 2 & 4.

<sup>&</sup>lt;sup>87</sup> *Ibid*, p. 4.

deadliest form of severe acute malnutrition.<sup>88</sup> These NGOs single out the sub-Saharan region in Africa and several countries in Asia as having rates of over 10% acute malnutrition in children.<sup>89</sup> A 2008 WHO brief on the consequences of the food crisis in Africa predicts that the number of malnourished children will increase by over 10% for wasting (emaciation or thinness as measured by low height for one's weight) and 40% for stunting (growth retardation indicated by low height for age).<sup>90</sup>

To sum up, with the tragic but clear observation of the 2009 UNICEF report, the 30. combined effect of the food, fuel and financial crises which are intensifying malnutrition and hunger "violate the rights of every child to food, education, good health and protection".<sup>91</sup>

31. Previous medical studies have pointed to the link between economic crisis, shortages in food and the incidence of noma. Some specifically identify the declining food supplies in the 1980s in Sub-Saharan Africa and the subsequent severe chronic malnutrition as one of the explaining factors of the reported increase of noma.<sup>92</sup>

Based on the undernourishment and malnutrition estimates put forward by UN agencies 32. and NGOs and on the experience of past food shortages, it can be concluded that the incidence of noma among children living in poverty will highly likely rise as a consequences of the recent food and economic crisis.

## C. Initiatives to Combat the Disease

#### 1. WHO, national governments and non-governmental cooperation

Prompted by reports from some governments and several NGOs about the recrudescence 33. of noma, the WHO organized the first information session on noma at the World Health Assembly in 1989.<sup>93</sup> This was followed, in 1994, by the adoption of a five-point action program against noma, which comprised:

- Prevention ensuring training and awareness on early diagnosis and treatment for each public health structure and raising awareness and informing populations, especially mothers:
- Epidemiology and surveillance finding out the incidence and incorporating noma surveillance into existing epidemiological surveillance systems;

<sup>&</sup>lt;sup>88</sup> Action contre le Faim and Médecins sans Frontiers, *supra* note 79, p. 3.

<sup>&</sup>lt;sup>89</sup> Countries with over 15% acute malnutrition: Burkina Faso, Chad, Democratic Republic of Congo, Eritrea, Lao People's Democratic Republic, Madagascar, Mauritania, Sudan, Yemen; countries with over 10% acute malnutrition: Bangladesh, Central Africa Republic, Comoros, Ethiopia, Guinea, Guinea Bissau, Haiti, Mali, Myanmar, Namibia, Nepal, Niger, Nigeria, Pakistan, Sierra Leone, Somalia, Timor-Leste, Togo. *Ibid.* <sup>90</sup> WHO, Regional Office for Africa, *The Global Food Crisis: Implications for the Health of People in the African* 

*Region*, 2008. <sup>91</sup> UNICEF, "A Matter of Magnitude", *supra* note 71, p. 3.

<sup>&</sup>lt;sup>92</sup> Other factors are: overcrowded living conditions, deteriorating sanitation, exposure to microbiological agents of disease: D.E. Barmes, C.O. Enwonwu, M-H. Leclercq, D. Bourgeois and W.A. Falkler, see supra note 18, p. 1112.

<sup>&</sup>lt;sup>93</sup> Kurt Bos, Klaas Marck, *supra* note 15, p. 15.

- Etiological research establishing the causes of noma and why it develops in some children but not in others;
- Primary health care including making sure that the necessary antiseptics, drugs and nutritional supplements are available.
- Surgery and rehabilitation.<sup>94</sup>

34. In 1998, the WHO Regional Committee declared the disease a priority on the African continent.<sup>95</sup> Following a decision of the Regional Consultative Committee in 2000, the Noma Program activities were transferred from the WHO headquarters in Geneva to the WHO Regional Office for Africa.<sup>96</sup>

35. In the African region, some progress has been achieved. It is essential to note the involvement of NGOs, charities and private individuals. These have been the driving force of the fight against noma, offering financial, logistical and medical support and assistance. To exemplify, the Noma Hospital in Sokoto, Nigeria (the only facility in Africa dedicated to treatment of noma) has been established at the initiative and with the funding of AWD-Kinderhilfe from Germany, the Dutch Noma Foundation and Facing Africa from England with the cooperation of Nigerian authorities.<sup>97</sup> To date, activities in the fight against noma have been implemented mainly in Africa, in Angola, Benin, Burkina Faso, Ethiopia, Lesotho, Madagascar, Mali, Niger, Nigeria, Uganda, Democratic Republic of Congo, Senegal, Togo, Zambia and Zimbabwe. Grants and funding from several private foundations and NGOs have been awarded to the WHO Regional Office over longer periods to finance these activities.<sup>98</sup> It appears that the lack of funds made it impossible to expand the programs on noma to the Asian and Latin American continents, despite the fact that both regions have documented cases of noma.<sup>99</sup>

36. Some steps forward have been made in terms of information and raising awareness on noma issues. With the help and financial support of a coalition of NGOs, the International Noma Day took place in Geneva on the 22 May 2008.<sup>100</sup> On the other hand, when accessed in June 2009, the website of the WHO Regional Office on Africa dedicated to the noma disease shows to have been last updated on13 February 2008 for the English version<sup>101</sup> and on 13 October 2004 for the French version.<sup>102</sup> Yet, disseminating information and raising awareness through any means about this deadly disease during a crisis period when malnutrition as the key risk factor has considerably increased is critical. While the goodwill and the competence of the WHO

<sup>97</sup> See <u>http://www.nomahospital.org/00000094b31422c06/00000095750d56b09/index.html</u>.

<sup>&</sup>lt;sup>94</sup> D.M. Bourgeois, M-H. Leclercq, *supra* note 51, pp. 153-154.

<sup>&</sup>lt;sup>95</sup> "The World Health Organization Action Against Noma – Some Important Landmarks", *Noma Contact*, WHO, p. 2.

<sup>&</sup>lt;sup>96</sup> Consultative Meeting on Management of the Noma Programme in the African region, Final Report, Harare, Zimbabwe, 19-21 April 2001; Kurt Bos, Klaas Marck, supra note 15, p. 15.

<sup>&</sup>lt;sup>98</sup> Noma: The Face of Poverty, The International Noma Day, No Noma International Federation, Winds of Hope Foundation, WHO, World Dental Federation, 2008; "The World Health Organization Action Against Noma – Some Important Landmarks", Noma Contact, WHO, p. 2.

<sup>&</sup>lt;sup>99</sup> Noma: The Face of Poverty, The International Noma Day, No Noma International Federation, Winds of Hope Foundation, WHO, World Dental Federation, 2008.

<sup>&</sup>lt;sup>100</sup> *Ibid*.

<sup>&</sup>lt;sup>101</sup> See <u>http://www.afro.who.int/noma/introduction.html</u>, accessed on 2 June 2009.

<sup>&</sup>lt;sup>102</sup> <u>http://www.afro.who.int/noma/french/introduction.html</u>, accessed on 2 June 2009.

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Africa Regional Office remains unquestionable, more must be done in the fight against this disease.

## 2. Structural shortcomings

37. The current action framework against noma has three main structural shortcomings. The insufficient geographic reach represents the first major problem. By handing over the coordination to the WHO Africa Regional Office, it has been symbolically asserted that the presence of noma in other regions is insignificant. This however is difficult to assess in the absence of comprehensive data on noma incidence. As has been pointed out, clinical studies show that there are cases of noma in parts of Asia and that the frequency might be underestimated. Vulnerable groups from parts of the world outside Africa might be discriminated against when it comes to tackling the noma disease.

38. Secondly, noma remains insufficiently prioritized at global and regional level. Despite having an associate mortality rate comparable with diseases such as acute upper respiratory infections, multiple sclerosis and appendicitis, noma does not appear in annual WHO reports.<sup>103</sup> Moreover, noma is not listed among the major killers like malaria, diarrheal diseases, HIV-infection/AIDS, measles, tuberculosis, and severe chronic malnutrition, however it is a complication of these diseases.<sup>104</sup> As such and following plain logic, it should receive more attention. Noma is the clearest indicator of extreme poverty, yet it does not attract the attention of the World Bank, which has as mission the reduction of global poverty.<sup>105</sup> For example, the common 1996 World Bank/WHO publication *The Global Burden of Disease* does not make any mention of noma.

39. There is a vicious circle at play. One the one hand, the absence of noma from WHO and public attention is explainable by the lack of data on the disease, given that no proper monitoring system exists to date. On the other hand, the lack of information about noma in the WHO reports keep the disease anonymous to most of the world and probably reduces the chances that such a system be put in place. In the end, the lack of prioritization affects the possibility to fundraise and the capacity to combat the disease on the ground.

40. Thirdly, noma is not addressed from a human rights perspective, despite being a human rights issue. This report insisted on the links between noma and the right to food of the most vulnerable members of society, children living in poverty. Furthermore, the right to water, the right to adequate health care and not least the right to life are at stake. Addressing noma from a right to food perspective has implications for States and their obligations under international human rights law, as well as for international organizations in their response to noma and malnutrition. In order for States to uphold the non-discrimination obligation, alone or via international organizations, they are required to identify the vulnerable groups through mapping and disaggregated data and to address the causes of noma – such as malnutrition and lack of vaccinations. Adequate aid and assistance should be directed with priority to these groups. Research on the causes and most effective ways of prevention and treatment of noma should be prioritized as well. While they have kept the fight against noma alive, it cannot be left to few

<sup>&</sup>lt;sup>103</sup> Alexander Fieger *et al*, *supra* note 41, p. 405.

<sup>&</sup>lt;sup>104</sup> C. O. Enwonwu, *supra* note 62, p. 43.

<sup>&</sup>lt;sup>105</sup> Alexander Fieger *et al*, *supra* note 41, p. 405.

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charities and private individuals to deal with such a terrible and endemic disease as noma. States and international organizations should step up to their human rights obligations, in particular the correlative obligations deriving from the right to food, and thus properly address the noma disease and assist its current and potential victims.

#### **II. RECOMMENDATIONS**

41. Noma is killing, disfiguring, and destroying the lives of children. The persistence of noma in today's world raises doubts not only about our morality, but it also comes to prove that the right to food of the children, the most vulnerable members of the international community is being severely violated. Malnutrition is the main predisposing factor of noma; malnutrition is easily treatable. To respect, protect and fulfil the right to food in respect of the most vulnerable groups affected or at risk of being affected by the noma disease, the following steps should be taken:

- The fight against noma must be made a priority at international level. A global monitoring system that does not rely solely on clinical data but on information collected at community level would be a first step towards true prioritization. While Africa is the most affected continent, medical studies show that the disease is present in other regions. In the view of the rise in malnutrition, all regions at risk must be included in the monitoring system. An international program of action needs to be drafted, based on the needs of vulnerable groups from all regions.
- Inter-agency cooperation on the issue of noma must take place. Agencies offering humanitarian and financial aid must take into account this disease and its risk factors and cooperate to address them. Food aid should be adequate in terms of nutrients in order to prevent malnutrition; vaccination campaigns for measles and other infections should be directed to the known noma hotspots. Financial schemes that address poverty should not overlook noma, since it is the very face of poverty and hence an indicator of urgent need for action. Noma should become integral part of the international response given by the organizations such as FAO, WHO, UNICEF, the World Bank etc to the challenges posed by the food and economic crises. Noma could be addressed by the High Level Task Force on Food Security, for example by prioritizing countries with incidents of noma for social protection programs.
- States must put in place national programs against noma or strengthen existing frameworks. States should allocate sufficient funds for prevention and information activities, as well as for nutritious food aid to those facing malnutrition. In case of lack of funds and faced with emergency situations, States have a legal obligation to appeal for international humanitarian aid. Not making such an appeal would be an encroachment on the right to food. Other States have a responsibility to cooperate as it is clear from Article 2 (1) and Article 11 (2) of the International Covenant on Economic, Social and Cultural Rights and from customary international law.

#### ANNEX



Source: Noma Contact, WHO, July 2006; Cyril O Enwonwu, William A Falkler Jr, Reshma S Phillips, "Noma (cancrum oris)", The Lancet.



Source: M. Leila Srour, Bryan Watt, Bounthom Phengdy, Keutmy Khansoulivong, Jim Harris, Christopher Bennett, Michel Strobel, Christian Dupuis, and Paul N. Newton, "Noma in Laos: Stigma of Severe Poverty in Rural Asia", *American Journal of Tropical Medicine and Hygiene*, 78(4), 2008.

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